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**Department for Work and Pensions**

**Research Report No 189**

# **Medical evidence and Incapacity Benefit: Evaluation of a pilot study**

**Roy Sainsbury, Anne Corden and Naomi Finch**

A report of research carried out by the Social Policy Research Unit, University of York on behalf of the Department for Work and Pensions

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First Published 2003.

ISBN 1 84123 594 6

Views expressed in this report are not necessarily those of the Department for Work and Pensions or any other Government Department.

Printed by The Charlesworth Group (Huddersfield, UK).

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# Acknowledgements

Thanks are due to all those people who took part in the research, and spent time talking to us about their views and experiences. Included here are the people who had claimed incapacity benefit; GPs and practice staff; staff in Jobcentre Plus; staff in the Leeds Medical Services Centre and doctors working in the Sheffield Medical Examination Centre.

Jo Bacon managed this project for the Department for Work and Pensions, and we are grateful for her help throughout. We also thank members of policy branches of the Department for Work and Pensions and project staff of SchlumbergerSema for their help and interest.

The team of researchers, which undertook the fieldwork, included Peter Kemp and Hanif Ismail. The administrative support for the project from Sally Pulleyn, Teresa Frank, Sarah Starkey and Julie Williams was essential. Thanks go particularly to Sally Pulleyn who had major responsibilities in supporting the fieldwork and who prepared the manuscript.



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# Summary

## Chapter 1: Introduction

The background to this research was policy concern with current arrangements for collecting medical information from certifying medical practitioners for use in determining entitlement to state incapacity benefits. Inadequate and low quality information collected from some certifying medical practitioners can lead to inefficiencies in the system resulting in unnecessary demands on sick and disabled people; procedural inconsistencies and frustrations, and inappropriate and wasteful use of DWP, Medical Services and Appeal Service resources. In addition, current arrangements create an unwelcome burden of work for some certifying medical practitioners, most of whom are GPs (Section 1.1).

The Better Medical Evidence Gathering pilot was undertaken in Sheffield and Rotherham in 2002, as one of a number of initiatives designed to improve advice and decision making for incapacity benefit. The aim of the research reported here was to evaluate this pilot (Section 1.2). A qualitative approach was appropriate, seeking views and experiences from the main actors: claimants, GPs and practice staff, processing staff and decision makers in Jobcentre Plus and Medical Services, and approved doctors (Section 1.3).

Determination of entitlement to incapacity benefit is a complex process involving collection of information from the claimant and their GP, consideration of this documentation by approved doctors, medical examinations for some claimants, and decision making by Jobcentre Plus staff. The essential difference between current arrangements and those in the pilot was that rather than asking GPs to provide information to the approved doctor (medical officer) on the standard report forms, medical information was extracted directly from claimants' GP record. Both the GP and the client themselves needed to consent to this new arrangement (Section 1.4).

## Chapter 2: Views and experiences of GPs and practice staff

Views and experiences were sought from GPs and administrative staff in 29 practices in the pilot area, of which 17 had agreed to take part in the pilot and 12 had declined.

It appeared that the view of the practice manager could be highly influential in initial decisions about whether to take part in the pilot. The main attractions had been the saving in GPs' time and reduction of form filling, and provision of a more balanced picture for benefits decisions. GPs who remembered declining to take part had concerns about patient consent and confidentiality. Some saw potential risk of loss of or damage to records, or records being away when needed (Section 2.1).

There was mixed evidence of any impact of the pilot on GPs themselves. Reduction in workload had been noticed mainly by GPs who usually dealt with higher numbers of IB113 report forms or spent some time completing each form. GPs reported no negative impacts for themselves or patients. In terms of administrative work required, the process was quickest and easiest for practices sending actual GP records. Practices sending photocopied records found this time consuming, and considered the additional honorarium insufficient. The arrangements for collection and return of records generally worked well (Section 2.2).

GPs had differing views on completing IB113 forms for patients claiming incapacity benefits, which influenced their overall feelings about the pilot arrangements. GP records were generally felt to provide fuller information, which could lead to better benefits decisions and save GPs some time. There remained some concerns about patient consent to release of full records, patient confidentiality, and the low quality of some records. Initial concerns about the practicalities of transferring the information decreased during the interview, as understanding grew (Section 2.3).

## Chapter 3: Views and experiences of incapacity benefits claimants

The claimant study group included 22 claimants who were pilot participants and ten non-participants.

Not everybody in this group was aware of their relationship to the pilot, and some initially recalled little about it. Those who remembered making a decision about taking part had known that participation was voluntary (Section 3.1).

People did not need full understanding of details of the pilot in order to agree to take part. Reasons for taking part fell into two groups: possible direct consequences for themselves and other claimants, and perceptions of the new arrangements as a generally better way of doing things. For example, some people hoped that by taking part they would avoid a medical examination, while some believed generally that advances in society required readiness to try new things. Just feeling that they had nothing to hide could be sufficient. Reasons for not taking part were remembered by only a small group of people. Mentioned here were issues of confidentiality and other concerns about possible negative outcomes for themselves (Section 3.2).

Not everybody was interested in what actually happened during medical assessment for incapacity benefits, but most thought that DWP would look at what they themselves had written on the standard forms and seek some medical information as proof of entitlement. People generally suggested their GP as one source of such information; other suggestions included hospital and clinic staff, and employers. There was a general perception that everybody receiving incapacity benefit would eventually be asked to have a medical examination. Long-term incapacity benefits claimants had the best grasp on the overall procedures (Section 3.3).

Claimants' views on the pilot arrangements were likely to depend partly on their relationship with their GP. There was wide variation here. Similarly, there was variable knowledge about what was contained in GP records. There was general acceptance of the importance of medical examinations in assessment for incapacity benefit, even among people with previous bad experiences (Section 3.4).

Towards the end of the research interview, when some claimants were better informed about the pilot, people weighed up advantages perceived against potential negative effects. There were a number of arguments on both sides (Section 3.5).

Most of those who had taken part in the pilot were content to have been included, although some wished they had understood more at the time. Most people recruited as non-participants appeared more positive about the new arrangements by the end of the discussion. People were interested in the pilot as a way of testing a new idea. Most felt it would be all right to introduce the new arrangements nationally, although some felt other claimants and some GPs would not like this, and some were puzzled as to how consent would be dealt with. People stressed the importance of maintaining confidentiality, and careful handling and speedy return of GP records. The small number of people who disagreed with the new arrangements had strong negative views (Section 3.6).

## Chapter 4: Administering the pilot arrangements

Group discussions with three teams of Jobcentre Plus administrative staff were conducted at the end of the implementation of the pilot. The main impacts reported by processing staff were an increase in the number of administrative decisions required, and more clerical and manual work in dealing with claims. One contributory factor was that no new computer programmes were inserted for managing the pilot. Other factors included complexities arising from apparent changes in status of individual claimants between 'participant' and 'non-participant' while their claim was dealt with. Some changes in staff instructions in the early part of the pilot also required new learning. Looking back, staff would have liked more IT support, and more overall support and information during the pilot.

The pilot increased the number of telephone enquiries from claimants, but there were few calls from advisers or health/care professionals.

On balance, it was thought better to have run the pilot than not, when considering a major change in procedure. The processing staff involved in the pilot now have key information and expertise on which to draw if decisions are taken to develop or extend the new arrangements (Section 4.1).

At the Leeds Medical Services Centre the team leader who oversaw administrative work reported that the pilot required a number of new procedures and additional work. This was not in itself problematic. Should the pilot be extended, attention is required to the resource implications for collection of GP records and their secure handling and storage. Different kinds of consent procedures would make administration easier (Section 4.2).

## Chapter 5: Using GP records in the administration of incapacity benefit

Approved doctors provide Decision Makers with advice about whether a claimant should be exempt from the Personal Capability Assessment (PCA) and about whether a client undergoing the PCA requires an examination. Their additional task under the pilot arrangements was to extract data from GP records and prepare a new report (form SB2) which summarised the relevant evidence from the GP notes. All of the approved doctors who prepared the SB2 reports were interviewed.

Advising whether a claimant's condition was likely to meet the legal requirements for exemption from the PCA was reported to be generally relatively straightforward. The GP records were thought to contain more information than most IB113 forms, and often allowed doctors to form a view about the severity of the condition, which could be helpful. Fuller information led to an increased level of confidence. There was a preference for using GP records to make decisions about exemption, although the process was thought to take slightly longer. The impact on the substance of decisions made was thought to be marginal (Section 5.1).

The process of extracting data from GP records, under the pilot arrangements, was defined under administrative rules. Extracts relevant to the claim were copied directly from the GP records, and additional notes made by the approved doctor drawing attention to any relevant gaps, or highlighting specific issues for the benefit of the subsequent examining doctor.

Two different approaches to extraction of data emerged, with respect to what kind of data was thought relevant, and the amount of, and type of, information extracted had sometimes changed over the course of the pilot. Points made consistently were that GP records varied considerably in quality (content and legibility) and were not geared towards assessing a patient's functionality.

Gaps in the claimant's medical history were not usually followed up with the GP, nor were GPs asked for further information if their records were illegible (Section 5.2).

The view of the approved doctors was that the proportion of PCA cases scrutinised where the advice was to call the claimant for medical examination had probably increased under the pilot arrangements. Contributory factors included having more relevant and up-to-date information, more extensive information, and more accurate information (Section 5.3).

Overall, there was preference for providing advice to Decision Makers based on GP records. These were available in all pilot cases. GP records varied in quality but compared favourably with quality of information on IB1 13 forms and Med4s, and often provided more accurate, more objective and more up-to-date clinical information. Disadvantages were that GP records contained little direct information about functionality. One criticism of the pilot was that the administrative rules were too rigid with respect to the time span of the information to be extracted (Section 5.4).

## Chapter 6: Using extracts from GP records in the administration of incapacity benefit

Approved doctors who provide advice to Decision Makers on the paper evidence and approved doctors who provide advice following an examination, were the principal users of the information extracted from the GP records (i.e. the information on the SB2 form). This information was also made available to decision makers in Jobcentre Plus who are responsible for making the decisions on benefit entitlement. The researchers interviewed all six approved doctors conducting regular medical examinations of claimants under pilot arrangements. Views were sought from all ten decision makers in Sheffield and Rotherham in six individual interviews and one group discussion.

The role of the incapacity benefits approved doctor, acting as an Examining Medical Officer (EMO) is to conduct medical examinations with incapacity benefits claimants and write medical reports for use by decision makers. In preparing for the examination, EMOs have access to all relevant documentation held by DWP relating to the claimant. They use this to identify aspects of medical history or functionality for exploration in the medical examination. EMOs did not mention to claimants in the pilot that they had access to extracts from their GP records, to avoid damaging relationships between patients and GPs (Section 6.1).

EMOs said they had been surprised that the pilot arrangements had little impact on the process of examining claimants or their choice of descriptors of functionality in their reports. Possible explanations included a usual lack of information about functionality in the extracts from GP records. In comparison, they could collect themselves a substantial amount of relevant information during an examination. However, some EMOs liked having fuller medical histories from GP records, and for some claimants fuller information meant EMOs could set a longer re-referral date.

All EMOs spent more time on their reports under the pilot arrangements. Some felt their advice about descriptors was better justified; none experienced an adverse effect (Section 6.2).

EMOs compared using extracted information on SB2 forms with information supplied by GPs on IB113 forms, under pilot and usual arrangements, respectively. Although most felt IB113 forms had greater potential for generating information about functionality, in practice many such forms contained little or none. Some EMOs felt the SB2 forms contributed to greater objectivity. There were mixed views about whether it was necessary to consider information from the last five years of GPs' records. EMOs agreed that neither the pilot nor the usual arrangements were designed to generate information directly from other health professionals, but there were differing views as to whether this omission was important. The IB113 forms could be easier to understand if the GP gave a coherent summary of the claimant's health. Piecing together a medical history from chronological extracts on the SB2 could take longer. Legibility of GPs' records remained an issue under both arrangements (Section 6.3).

There was no consensus of preferences for the pilot or usual arrangements. Preferences for the pilot arrangements were based on the guarantee of at least some information from the GP, a more complete clinical picture, and more objective information. Disadvantages included an additional time requirement (reading and writing reports) and lack of direct information about functionality. The main advantage of working with the IB113 forms was that questions were designed to elicit relevant information about functionality (Section 6.4).

Most of the Jobcentre Plus decision makers' work is concerned with claimants where the medical evidence indicates that they have not met the PCA eligibility criteria, usually following a PCA medical examination. Decisions are usually hardest to make when claimants score themselves above the threshold but the advice from the EMO indicates that they score below the threshold. What decision makers require here is good quality information. Any factual information from the claimant's own doctor, usually the GP, is considered alongside the claimant's choice of PCA descriptors and the EMO's evidence and advice (Section 6.5).

Decision makers had been surprised and disappointed that the pilot arrangements had little impact on the quality of medical reports produced by EMOs, or the substance and quality of their own decisions. Certainly, medical reports written for pilot cases generally included justification for choice of descriptors, but what was written was not always useful. Some decision makers were definite in their view that their decisions would have been exactly the same under usual arrangements. Those who had seen fewer cases found it hard to make an assessment here. There was no feeling that the pilot arrangements had increased confidence in decisions (Section 6.6).

Decision makers reflected on experience of using SB2 forms in comparison with IB113 forms and Med4s. In terms of usefulness, a common perception was that much clinical data contained in the SB2 was hard for them to understand and interpret, especially if there were technical terms or diagrams in GP records. They felt unable to use much of what was in the SB2 forms. IB113 forms, well completed by GPs, were generally better at providing information about functionality, but failure to return IB113 forms and paucity of information in some was a problem. Legibility of handwriting was a source of continuing concern and frustration, and decision makers were surprised that approved doctors were not transcribing more of the information on the SB2. Extracts on SB2 forms ending in mid-sentence could raise doubts about missing information, and reduce confidence in decisions (Section 6.7).

Decision makers expressed no strong views about preferences for working with the pilot or usual arrangements, and there was no consensus. Some felt the principle of the IB113 was superior, but in

practice produced variable information and sometimes none. Some felt it was better to have at least some information from GPs for all decisions (Section 6.8).

## Chapter 7: Developing policy for the collection of medical evidence

A number of policy issues emerge from this study which will need consideration in any reforms to incapacity benefit procedures.

One issue is the acceptability of using GP records. It is possible to design systems for collection and return of GP records which would address objections in terms of the practicalities for GPs and claimants. Objections in principle on grounds of confidentiality are likely to remain for some.

More robust methods of increasing claimants' understanding and seeking their consent should be explored, and could help to persuade more GPs that their patients have given fully informed consent.

The amount of additional administrative work created for practice staff was variable, and raises issues about any additional remuneration. Thinking about future arrangements will need to take account of the diversity in, and possibilities of the use of, information technology. Practice managers played key roles during the pilot and their views will be particularly important.

Overall, GP records are useful in providing evidence of diagnosis of health conditions, but less useful for judging functionality. The IB113 form can be useful on both counts if filled in well, but this does not happen sufficiently often. It is hard to prescribe with any certainty but, for new claimants, an extract from the GP records covering the last 12 to 24 months may be satisfactory. There was no consensus among the professionals about the value of information collected from additional sources, although claimants felt this could be important.

Further work is necessary to evaluate what impact there might be on the appeals system from the pilot arrangements (Section 7.1).

The research has provided some lessons about running a pilot which could be useful in future evaluations (Section 7.2).

The study had provided suggestions for improving the collection of medical information in the future. In terms of revision of the current IB113 form, flow and quality might be improved by introducing different systems for remunerating GPs; taking more proactive management action for non-compliance with GPs' terms of service; quality control procedures and enhanced GP training. In terms of building on the pilot arrangements, suggestions were aimed at increasing operational effectiveness and efficiency. Other ideas included different combinations of administrative process (Section 7.3).

The report ends by returning to the research aims (Section 7.4). The pilot has had mixed results. The effect at the level of the individual GP was only noticed in particular practices. Among the users of medical information, approved doctors preparing the SB2 report (case note extract) and providing advice to decision makers on paper evidence were closest to the raw material of the GP records and found them the most useful. There was no consensus among the EMOs about which arrangements were preferable. For decision makers information on SB2 forms was generally of less use than information on the usual IB113 forms.

# 1 Introduction

This report presents findings from qualitative research to evaluate the Better Medical Evidence Gathering Pilot undertaken for the Department for Work and Pensions (DWP) in the Sheffield and Rotherham area during 2002. The aim of the pilot was to test alternative arrangements for providing medical evidence to approved doctors<sup>1</sup> who give advice to decision makers who determine eligibility for state incapacity benefits. These new arrangements would, it was hoped, improve the evidence gathering process for incapacity benefit, and the overall efficiency of the decision making process. The study was conducted by the Social Policy Research Unit (SPRU) at the University of York for DWP, and took place concurrently with the pilot during 2002.

## 1.1 Background and research

### 1.1.1 The policy context

During the past 12 to 15 years there has been considerable policy interest in long-term sickness benefits. This was prompted initially by a growth in the numbers of recipients<sup>2</sup>. The reasons for the increase are not straightforward, but it is thought that economic trends, demographic changes and benefit administration have all contributed to the rise (Department for Work and Pensions, 2002a). Benefit administration has also attracted the interest of the Social Security Select Committee (2000) and the National Audit Office (2001), who have identified problems with the current arrangements for incapacity benefits.

### 1.1.2 Concerns about the current arrangements

Incapacity benefit<sup>3</sup> is the main state benefit for people whose health or disability is deemed such that it is not reasonable to expect them to seek work as a condition of receiving benefit. People gain entitlement to incapacity benefit if they have National Insurance contributions on their earnings and

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<sup>1</sup> See Note on Terminology in Section 1.6 of this chapter for an explanation of the term 'approved doctor'.

<sup>2</sup> In 1979, 690,000 people received Invalidity Benefit and Invalidity Pension (the forerunners to the current incapacity benefits). By February 2002 the number on Incapacity Benefit had risen to 2.3 million.

<sup>3</sup> Incapacity Benefit is a generic term covering contributory Incapacity Benefit and Income Support (on the grounds of incapacity). Both provide a replacement income to people below state pension age who have to stop working or looking for work as a result of sickness or disability. If someone has low income, they can claim Income Support on the grounds of incapacity and may also be able to get income support to top-up their Incapacity Benefit where they have no other income.



they satisfy the relevant test of incapacity<sup>4</sup>. The incapacity benefit decision-making process relies on a questionnaire completed by the claimant, medical advice from an approved doctor (which may include evidence collected in a face-to-face examination) and factual evidence from the claimant's own doctor, usually the GP. Concerns with the process have included the adequacy and quality of the factual medical evidence collected from GPs. Staff involved in the advisory process sometimes feel that this evidence does not enable them to give confident and accurate advice and that subsequent decision making may be affected. As a result it is likely that:

- some claimants, who should be exempt from supplying additional information about themselves because of the severity of their condition, are not identified at an early stage in the assessment process and may be called inappropriately for a medical examination;
- some claimants who should be assessed on paper evidence as meeting the eligibility criteria are not identified and are called for an unnecessary medical examination;
- some claimants may be wrongly awarded incapacity benefit on the basis of inadequate medical evidence; and
- some disallowed claims are eventually overturned at an appeal tribunal when benefit should have been allowed earlier.

Such inefficiencies in the system are thought to result in unnecessary demands and additional stress on people who are sick or disabled; inconsistencies in procedure and decision making at the operational level; frustration for Jobcentre Plus staff who administer incapacity benefit and approved doctors who provide them with medical advice; and inappropriate and wasteful use of Medical Services resources. Other evidence suggests that the decision-making process could be improved. For example, there is a high level of success for claimants who appeal against disallowance - for the quarter ended March 2002, of those claimants who appealed against disallowance of benefit following a 'Personal Capability Assessment' (see Section 1.4) over 40 per cent had the decision overturned (Department for Work and Pensions, 2002b).

An additional concern is the amount of work created for GPs under current arrangements for determining eligibility for incapacity benefits (Cabinet Office, 2001, 2002). Recent research (Hiscock and Ritchie, 2001) has shown that completion of the required forms and reports represents an unwelcome burden of additional work to many GPs. Such factors may all affect the quality and consistency of medical evidence provided by GPs under the current system. Indeed, internal reports coming from the new Appeals Service refer, among other things, to the unsatisfactory quality of medical evidence produced by GPs.

The problems and concerns identified above have led DWP to examine the medical evidence gathering process for incapacity benefit and to consider ways of improving quality and efficiency. This has led to the introduction of a series of pilots with this aim. These are:

- The Better Medical Evidence Gathering Project. This is a DWP initiative undertaken in the Sheffield and Rotherham area during 2002 and the subject of this research study. The aim of the pilot was to test alternative arrangements for obtaining medical evidence from the claimant's own doctor.
- Evidence Based Medicine project. This is a joint Medical Services/DWP initiative to develop a computerised process to support the provision of advice following a medical examination.

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<sup>4</sup> If a person has not paid enough National Insurance contributions but satisfies the relevant medical test, he or she can get National Insurance credits.

- IB113 project. This project is also concerned with gathering factual evidence from the claimant's own doctor. It involves piloting a new version of the medical report form sent to GPs.

## 1.2 Research aims and objectives

This research was concerned with the Better Medical Evidence Gathering pilot. In order to inform future policy decisions, there was a need for information about the impact of the pilot. Policy makers sought information about the way in which the pilot was put into operation. They sought greater understanding of the way in which claimants, GPs, approved doctors and decision makers perceived and experienced the pilot arrangements and, specifically, the use of GP case records in making more informed decisions. More detailed information is intended to help policy makers achieve the most appropriate arrangements for providing medical evidence for incapacity benefit claims.

The aim of the research was to evaluate the Evidence Gathering pilot in relation to:

- issues for incapacity benefit claimants;
- the impact on GPs;
- the quality of medical advice given to decision makers;
- the impact on decision making; and
- the overall effectiveness of the new procedures.

Research objectives were:

- to explore whether the pilot arrangements promote appropriate high quality medical advice following scrutiny of documentation which would reduce the need for the claimant to undergo a medical examination;
- to explore whether the pilot makes available better quality medical information to doctors carrying out medical examinations, increasing their ability to give high quality advice to decision makers;
- to explore whether the pilot produced better evidence to help decision makers to make confident decisions;
- to explore understanding of the new arrangements and influences on participation among claimants and GPs; and
- to explore whether GPs, approved doctors and Jobcentre Plus staff find the process of gathering information from case notes workable and appropriate, and suits the needs and circumstances of claimants.

## 1.3 Research design and methods

A qualitative approach was appropriate for evaluating the Evidence Gathering pilot, its impact on GPs, approved doctors, decision makers and claimants, and their perception, views and experiences<sup>5</sup>.

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<sup>5</sup> The qualitative research complements the in-house analysis of administrative data designed to look at the characteristics of various groups of participating and non-participating claimants, and assess the impact of the pilot on incapacity benefit allowances and disallowances and the flows of claimants through various stages of the claiming and decision making process.

The researchers made initial site visits to the Sheffield Jobcentre Plus office, and the Leeds Medical Services Centre, for early discussion with staff about implementation of the pilot arrangements and issues arising.

In depth interviews were carried out with:

- new claimants participating in the pilot;
- new claimants not participating in the pilot;
- re-referral claimants participating in the pilot;
- re-referral claimants not participating in the pilot;
- GPs participating in the pilot<sup>6</sup>;
- GPs not participating in the pilot<sup>7</sup>;
- administrative staff in participating GP practices;
- approved doctors in the Leeds Medical Services Centre;
- approved EMOs operating in Sheffield and Rotherham;
- Medical Services operational manager for the pilot;
- Jobcentre Plus decision makers.

Group discussions were carried out with:

- Jobcentre Plus decision makers;
- Jobcentre Plus incapacity benefits processing staff.

The interviews and group discussions were undertaken in the Sheffield and Rotherham areas, the location chosen by the Department for Work and Pensions for this pilot<sup>8</sup> and at the Leeds Medical Services Centre. Appendices A-C contain details of the research methodology, including sampling and recruitment, research instruments used in interviews, and letters of invitation to take part in the study sent to GPs and to incapacity benefit claimants.

## 1.4 Administrative context

### 1.4.1 Current arrangements for the decision-making process for Incapacity Benefit

For those in employment, an incapacity benefit claim is usually only possible after they have satisfied the Own Occupation Test to get Statutory Sick Pay, which is paid for up to 28 weeks.<sup>8</sup> After 28 weeks, they are required to satisfy a Personal Capability Assessment (PCA), which is the medical test used to decide entitlement to incapacity benefit. All other claimants are required to satisfy the PCA from the beginning of their claim. The PCA provides an indication of the extent to which a person's condition

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<sup>6</sup> In four cases, practices managers were interviewed instead of GPs.

<sup>7</sup> One advantage of choosing this area was that some claimants' and GPs' experiences would have had experience of the Miners Compensation Scheme which uses a similar method of collecting information.

<sup>8</sup> This looks at whether ill health or disability stops a person from doing their normal job. A certificate (Med 3) from a medical practitioner, usually the person's GP is normally sufficient to satisfy the test.

affects their ability to do a range of everyday work-related activities covering:

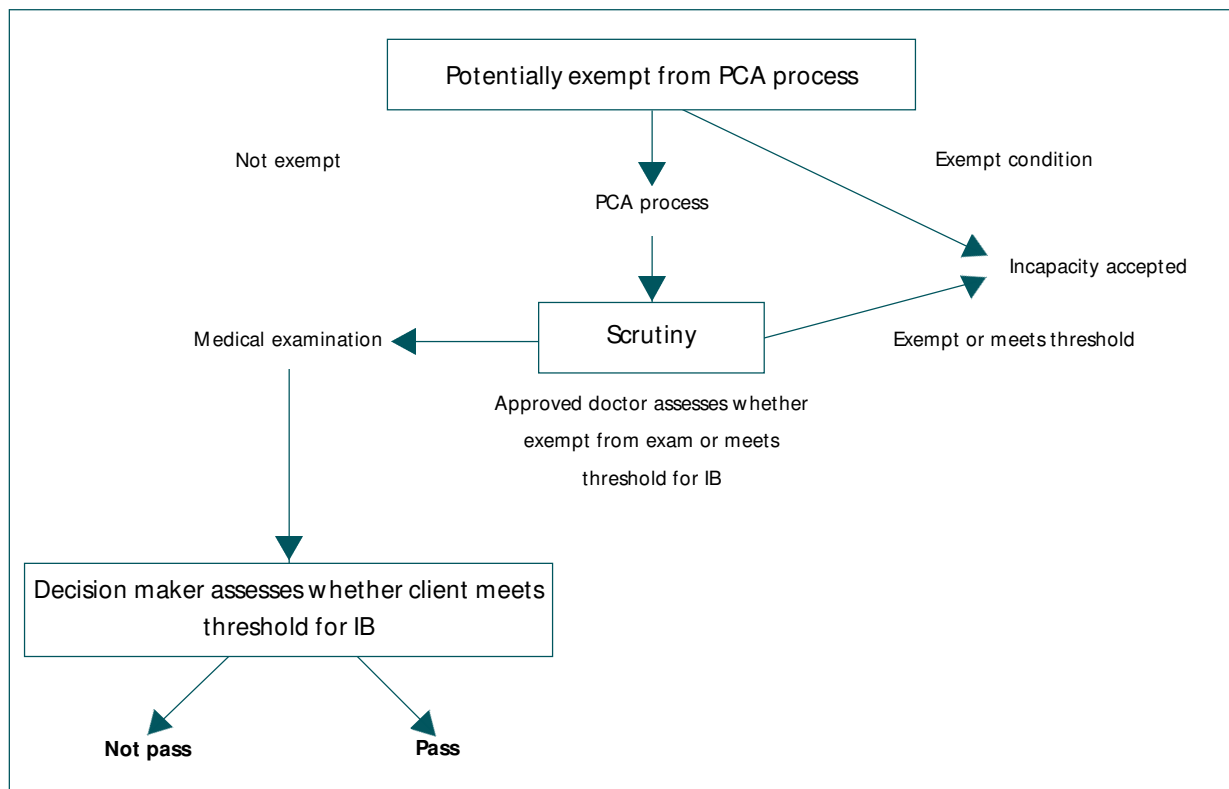
- physical functions such as walking;
- sensory functions such as ability to hear;
- mental functions such as interaction with others.

The PCA requires the collection of paper evidence to inform the decision-making process. This process is outlined in Figure 1.1 and detailed in the text below. A person may qualify for incapacity benefit on the basis of meeting the threshold for functional limitation in any one of the mental, physical or sensory activities, or on the basis of a combination of less severe limitation across several areas of function.

Following a claim to state incapacity benefit, before the PCA is first applied, benefit is paid if supported by evidence from the claimant's own GP. When the PCA is applied, those people who do not meet the threshold for incapacity are disallowed further incapacity benefit, have their award terminated, and are expected to seek work as a condition of receiving further benefit. For those people who do meet the threshold for incapacity, a date will be set for a further PCA to identify any change in a person's condition.

Appendix D provides a fuller explanation of the purpose of the PCA and the administrative procedures involved.

**Figure 1.1 The Incapacity Benefit decision-making process**



## 1.4.2 The Incapacity Benefit decision-making process

### Potential exemption from the PCA process

The first stage of the decision-making process is to establish whether the claimant is exempt from the PCA process. This stage is necessary in about a third of cases where there is some evidence to suggest that the claimant might fall into an exempt category. In many cases the decision maker will seek medical advice on this matter from an approved doctor. The approved doctor will seek factual information from the certifying medical practitioner (usually the claimant's own GP) on form IB113. Those with very severe medical problems are awarded incapacity benefit without having to go through the PCA process. In certain cases, Jobcentre Plus processing staff can make a decision whether to exempt the claimant from the process. These include claimants with a terminal illness, those in receipt of the highest rate care component of Disability Living Allowance and those with severe conditions like paraplegia, dementia and registered blindness. In other cases, such as mental illness, progressive impairment of cardio-respiratory function, or dense paralysis, the decision to exempt the claimant from the PCA process is undertaken following advice from an approved doctor.

Claimants who are not exempt are asked to complete a detailed questionnaire (form IB50) about the impact of their condition on a range of work-related activities as defined in the PCA. This asks the claimant to select from a number of options the statement that best explains any functional limitation they may have in each physical and sensory area listed. In the technical language of the decision-making process, this is referred to as making a choice of 'descriptors'. Each descriptor has an associated 'score' that is designed to represent the degree to which it affects activities of everyday life. If the claimant scores 15 points in any one activity, or a total of 15 points from a combination of activities, the threshold of incapacity is met for benefit entitlement purposes. A separate system of scoring applies to activities that are affected by the presence of mental health conditions (see section 1.4.3 below). Claimants are encouraged to provide any additional information that may assist the decision process or affect their ability to perform work-related activities. The incapacity benefit claimant returns the questionnaire (form IB50) to the Jobcentre Plus office along with a Med 4 statement from their own doctor, if the approved doctor has not already requested an IB113 report.

### Scrutiny

At the next stage of the PCA process, an approved doctor, working on behalf of the Department for Work and Pensions, considers whether the claimant's self-assessment (IB50) is supported by medical evidence that may be available from the IB113 or Med 4 (referred to as paper scrutiny). When a claimant's IB 50 scores above the PCA threshold, and this is supported by the available medical evidence the approved doctor will advise the decision maker to accept the score. Thus the claimant satisfies the PCA eligibility criteria for incapacity benefit (these are referred to as cases which 'pass on scrutiny'). Where there is a lack of available information or an apparent contradiction between the claimant's IB50 and the available medical evidence, the approved doctor will call for further evidence. This will usually be in the form of a medical examination of the claimant where an approved doctor (known as an Examining Medical Officer, or EMO) carries out a face-to-face medical examination with the claimant. The examining doctor will make an assessment of the level of functional ability in each of the activity areas and the presence of any non-functional restrictions. He/she will then prepare a detailed incapacity report for the decision maker (form IB85).

### Decision maker assessment of whether claimant meets threshold for incapacity benefit

Approved doctors then pass all the medical evidence in relation to the PCA to the Jobcentre Plus decision maker, who makes the decision on benefit entitlement. This decision is straightforward if the medical evidence (any evidence supplied by the claimant's own GP (Med4 and IB113) and the advice

of the approved doctors (IB85)) corresponds with information in the claimant's questionnaire (IB50). However, if there are inconsistencies, the decision maker will weigh up all the evidence before arriving at a decision on benefit entitlement.

### 1.4.3 Claimants with diagnoses of mental illness

A claimant who appears, on the evidence available, to have a mental health condition will be referred to an approved doctor for advice before an IB50 questionnaire is issued. Those with severe mental health conditions will be exempt from the Personal Capability Assessment process and treated as incapable of work. Claimants with a mild or moderate mental health problem will be sent the questionnaire (IB50) so that any other physical and sensory problems can be taken into account, as well as the effect of the mental health condition.

### 1.4.4 The Better Medical Evidence Gathering pilot

The Better Medical Evidence Gathering pilot was designed to test alternative arrangements for the provision of medical information that may reduce the problems identified with the current arrangements, bring improvements and increase efficiency. The objectives of the pilot were to identify arrangements for providing medical evidence that might:

- improve approved doctors' ability to identify the cases that meet the requirements of the medical testing process more quickly and without recourse to full medical examination;
- improve decision makers' ability to make allowance or disallowance decisions based on medical evidence, with greater confidence and with fewer decisions overturned at appeal;
- reduce the burden of Incapacity Benefit-related paperwork on GPs;
- reduce inefficient use of medical resources, particularly at examinations.

In order to achieve the above objectives, the current system of collecting medical evidence from GPs via the IB113 and Med 4 forms was replaced with a system where approved doctors sought access to the claimant's GP case records for the last five years and prepared an extract of relevant information onto a new form SB2. Table 1.1 shows the types of medical evidence available at different stages of the decision-making process and how this differed between the current and the pilot arrangements. The basic decision-making process (see Figure 1.1) remained the same.

**Table 1.1 Medical evidence: differences and similarities between the current and pilot arrangements at different stages of the decision-making process**

	Current arrangements	Pilot arrangements
Advice whether to exempt from PCA process	Application form (SC1) Case file IB113	Application form (SC1) Case file SB2
Scrutiny	Application form (SC1) Case file IB113 or Med 4 IB50	Application form (SC1) Case file SB2 IB50
Decision maker assessment of whether claimant meets threshold for Incapacity Benefit	Application form (SC1) Case file IB113 or Med 4 IB50 IB85	Application form (SC1) Case file SB2 IB50 IB85

The pilot began in January 2002 in the Sheffield and Rotherham area. All GP practices were invited to participate voluntarily. Claimant participation was sought over a ten-month period, which extended beyond initial expectations in order to generate sufficient claims under pilot arrangements to enable evaluation. Both those making a new claim for incapacity benefit and those who were having their claim re-assessed were invited to take part. Claimant agreement to take part in the pilot was sought on the incapacity benefit application (form SC1) and, for current claimants facing a PCA, on their questionnaire (form IB50). Claimants who did not opt out, and GPs who voluntarily agreed to take part, went forward into the pilot.

GP case records, or photocopies, were required within 15 days, and were sent by secure courier to Managers and Process of Claims Ltd. (MPC)<sup>9</sup> for scanning on to a CD and forwarded to the Medical Services Centre in Leeds. Case records were returned to GPs within three days (or immediately on request in case of emergency). It was possible for computerised records to be transferred as a print-out of the last five years' records. GPs received payment for the work involved in preparing IB113 reports for DWP medical officers and Med4 statements for patients through their overall NHS remuneration. In recognition of the potential additional work for the GPs and their staff, GP practices received an honorarium of £10 for each patient whose original notes were transferred during the pilot and £20 if photocopies of the notes were provided.

An approved doctor received the CD of the GP records and extracted relevant medical evidence to a new report form (form SB2). This report form was then available to provide evidence at the appropriate stage of the PCA medical advisory process (potential exemption, scrutiny and examination). The SB2 was also available to the Jobcentre Plus decision maker who made the decision on benefit entitlement. According to the information sheet prepared for GPs (DWP/Medical Services, V5, Jan 2002) the information extracted from the case notes was confined to:

- whether the claimant had a specific bodily or mental disease or disablement;
- whether conditions for exemption from a PCA were met;
- assessment of function restriction/limitation, arising from the disease or disablement;
- whether legally defined 'exceptional circumstances' applied; and
- the functional outlook or prognosis.

## 1.5 The framework of the report

Chapters 2 and 3 examine the GPs' and claimants' views and experiences of the pilot arrangements respectively. Chapter 4 investigates the administration of the pilot arrangements in Jobcentre Plus offices and in the Leeds Medical Services Centre. Chapter 5 explores the use of GP records for making decisions about exemption and for extracting information onto an SB2 form. In Chapter 6 we look at how the extracted information is used by EMOs and by decision makers. Chapter 7 presents a number of issues arising from the study that might inform future policy for the collection of medical evidence, and presents the conclusions of the qualitative evaluation of the pilot.

Appendices provide full details of research methods and the analysis of data. Appendix A includes details of the characteristics of the claimants who took part in the research. Appendix B contains topic guides used in interviews with research participants. Appendix C contains copies of letters sent to GPs and claimants. Appendix D provides a full explanation of the administrative context within which incapacity benefit claims are decided.

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<sup>9</sup> Towards the end of the pilot MPC were renamed Elision.

## 1.6 Note on terminology

Medical practitioners play a variety of roles in the administration of incapacity benefit. These are referred to in this report as 'approved doctors'. The key role of the approved doctor in the Medical Evidence Gathering Pilot included:

- preparing a data extract from GP case files (on form SB2);
- advising decision makers on paper evidence for exemption/scrutiny cases;
- advising decision makers following an examination of the claimant (when they act as an Examining Medical Officer (EMO)).

Incapacity benefit approved doctors may be:

- employed by the DWP directly (in DWP Corporate Medical Group);
- employed by SchlumbergerSema Medical Services (the company contracted to provide Medical Services to DWP); or
- subcontracted to Medical Services.

In relation to medical evidence gathering for Incapacity Benefit, NHS general practitioners' terms of service require them to provide certain information to a DWP 'medical officer' on request. The relevant legislation defines that a medical officer may be a doctor employed by DWP directly or by an organisation contracted to provide medical services to DWP. Doctors such as NHS general practitioners, who provide advice and statements of incapacity (so-called sick notes) to their patients as part of their clinical practice are known as 'certifying medical practitioners'. NHS GPs have a contractual obligation to provide such statements to their patients and to provide information subsequently requested by a DWP medical officer (DSS/DWP, 2000).





## 2 Views and experiences of GPs and practice staff

Our analysis begins by presenting the views and experiences of GPs and administrative staff in 29 practices in the Sheffield and Rotherham area, of which 17 had agreed to take part in the pilot arrangements and 12 had declined. Appendix A presents details of the selection and personal characteristics of the GPs in this study group and key characteristics of the practices in which they worked. The researchers usually spoke to the senior partner; in four practices they were asked to speak to the practice manager, as the person who knew most about the pilot.

Additional research interviews, with administrative and clerical staff with day-to-day responsibility for dealing with the requests for medical notes, took place in ten of these practices taking part in the pilot.

The first part of this chapter is concerned with GPs' initial views of the proposed new arrangements, and decisions made about whether to participate. The second part is concerned with the impact of the pilot arrangements for GPs and practice staff in those practices which took part in the pilot. Part 3 explains overall views on the pilot arrangements, as they emerged by the end of the research interview. GPs and practice staff weighed up advantages and disadvantages now perceived, after discussion with the researcher and, for some, through experience of being in the pilot.

### 2.1 Taking part in the pilot

#### 2.1.1 Awareness and understanding

At the beginning of the research interview, not all GPs could remember receiving the DWP invitation to take part in the pilot. This was especially the case among GPs who had declined to take part (non-participant GPs). Feeling '*overwhelmed*' by requests to take part in research meant that, unless the subject matter was of particular interest, GPs might pay little attention. Practice managers, who remembered the matter being discussed in practice meetings, were sometimes the main source of information about the initial reactions of GPs to the request from the Department.

Those who could remember requests to take part in the pilot reflected on their initial understanding of its purpose and what would be involved. Again, there was hazy recall among some of the non-participants. All GPs who could remember the process of considering the new arrangements and whether to participate said that there had been some consultation with other practice staff. It was common to put the matter on the agenda for the fortnightly or monthly practice meeting, and take

account of the views of other partners, the practice manager and sometimes other senior administrative staff, who would have day-to-day responsibility for dealing with the arrangements. It appeared that the views of the practice manager could be highly influential in encouraging participation.

The main aim of the pilot, as recalled in retrospect, was generally seen to be to reduce the workload of GPs. The pilot would show whether a potentially time-consuming task for GPs could be achieved in a different way. A small number of GPs, who had been especially interested in the pilot, remembered other aims: to provide better information about eligibility for benefits and to reduce the number of medical examinations. Among this group were GPs who were active members of Local Medical Committees and said that the pilot had been discussed at meetings they had attended. One GP suggested that the pilot could be seen in terms of helping people back to work, but did not elaborate on this.

Doubts about the purpose of the pilot were expressed by one GP who thought there would be some underlying '*political or financial goal*' which would not be in patients' interests.

In deciding whether to take part in the pilot, GPs and practice staff weighed up possible advantages against any concerns.

### 2.1.2 Agreeing to take part

Among the group of practices which had decided to participate in the pilot, some saw only advantages in the new arrangements. Others had some initial concerns but these were resolved.

The main attraction of the proposed new arrangements was that they could save GPs' time, and reduce the number of forms they had to fill in. This duty was generally disliked, even if perceived as part of the GP's job. This was not just because of the time involved, but also because doctors often felt they could not answer questions asked for benefits purposes, or felt that some of the questions were inappropriate for a GP whose main responsibility was treating patients, dealing with their illnesses and maintaining health.

Additional work likely to fall on practice administrators and clerical staff had been considered but, in this group of participants, was perceived as unlikely to be high, and certainly manageable. Practice managers who had experience of similar arrangements of collection and return of patients' notes for the miners' compensation scheme had not met problems here.

Not all participant GPs remembered thinking about possible outcomes for patients when they were considering whether to take part in the pilot. Those who did said they thought the new arrangements might lead to greater justice for patients, who were more likely to get what was rightfully theirs on the basis of more appropriate detailed information. Some GPs said that they did not have time to write much on the IB113 forms. Some said they felt slight unease about what they wrote, recognising that they were not always '*dispassionate*'. Examination by a third party might give a more balanced picture for benefits decisions, or, at least, no worse than the assessment possible from the GP-completed IB113. One GP thought that the pilot arrangements would mean quicker assessments, explaining that if GPs in his practice were busy or on holiday it could take three or four weeks to complete and return an IB113 form.

Apart from specific advantages perceived, some GPs said that they had been influenced by more general views. For GPs who felt it was time to review the provision of medical evidence for benefit purposes, this pilot was one step forward in the right direction. Another positive influence on deciding to take part was feeling definitely in favour of research and development for the advancement of general practice, and wanting to be part of this.

A number of initial concerns were recalled, but these had been addressed in practices which agreed to take part. Some GPs and practice managers felt it essential that patients' notes and records were always available in the surgery, in case patients came in for consultation, needed treatment or repeat prescriptions. A number of medical and non-medical staff might require immediate access to patients' notes. This concern was addressed by the photocopying option, by the Department's reassurance of immediate return of notes if required or, as explained in Section 2.2, by development in some practices of administrative processes to avoid problems arising.

It was considered important that patients had given their informed consent, and there were some initial concerns about how this was going to be handled. GPs in participating practices had been satisfied by explanations from the Department of the way in which patients agreed to their notes and records being used.

There were also concerns about the confidentiality of information about patients which left the surgery. Initial reassurance came from telephone explanations about how the data would be transported and dealt with, which courier firm would be involved, and which Medical Services staff would see the case notes. Again, administrative processes were introduced in some practices to help maintain confidentiality, as explained in Section 2.2.

One GP remembered wondering whether taking part in the pilot would result in additional demands on the practice in terms of reporting back. Being told that any such further participation would be voluntary had been reassuring.

The payments for participation offered by DWP were generally not very important in decisions to take part. Practices which opted for photocopying sometimes said they thought in retrospect they had not thought hard enough about the payment levels.

### 2.1.3 Deciding not to take part

As explained earlier, not all non-participant GPs could recall being invited to take part in the pilot, and some did not know why their practice had decided against participation. Also in the group were GPs who explained that the invitation had come at an awkward time, coinciding with a change of practice manager or installation of a new computer. In these circumstances, most external requests which would require extra work or different ways of working for administrative staff were being turned down. Had their invitation come at a different time, it might have been considered differently. There was, therefore, a relatively small number of GPs who remembered declining to take part in the pilot on matters of principle or because the pilot compromised normal ways of working. Those who did remember had strong views, which were often based on negative personal experiences.

The possibility that records would be out of the surgery when required could be a strong negative influence, as could potential danger of loss or damage in transit, or return of notes and records filed in the wrong order. Both GPs and practice managers saw risks here. In these practices the photocopying option which might address this concern had appeared to require considerable additional administrative resources. In practices in which administrative staff were '*already overloaded*' or premises cramped, extra photocopying was not wanted. Interestingly, in some of these non-participating practices, experience of the miners' compensation scheme was that staff came to the practice and scanned notes and records themselves, using their own equipment and paper. This seemed a better model, and thus did not encourage participation in this pilot.

It was not always clear why the DWP had considered there to be any potential gain for practices. The level of additional payment, in the form of an honorarium for participation, appeared to offer them little or no financial incentive. Some GPs also thought the overall costs of the proposed new arrangements would be higher for the Department.

There was concern about who would have access to the records once they left the surgery. One GP remembered previously seeing patients' incapacity benefit case files lying on the floor in a medical examination centre. His view was that the pilot was unethical and breached the commitment given to patients about their confidentiality. There were general concerns about whether patients would be giving consent, and if they would, whether they would fully understand the range of information about them that would be available to the approved doctors (DWP medical officer). It appeared possible, to the researchers, that some decisions not to take part had been made quickly on the basis of concerns about informed consent and confidentiality, without full understanding of how and when consent was sought, or how notes and records would be handled.

Another strong view was that the GP is the best person to provide the medical information required. One GP who had experience in a separate capacity of using medical information drawn directly from GPs' records, felt that the quality of some records was so poor that a system based on such records would be unworkable. One practice had already gone a long way towards development of what seemed a better way of providing information - using software templates to lift appropriate data from electronic records to fit different benefit forms. For them, the pilot arrangements seemed a step backwards.

As already pointed out, we do not know how far some of the concerns were based on incomplete information or misunderstanding, or whether, and how far, any staff pursued initial concerns or sought further information before declining to take part. We do know from interviews in participating practices that phoning for clarification, further information or reassurance was often important in agreeing to take part.

## 2.2 The impact of taking part

Not all the practices in this study group who had agreed to take part in the pilot had actually received requests for records thus far. The GPs concerned (from three practices) were surprised about this, and there was some disappointment that they had not had an opportunity to test the new arrangements themselves. We do not know the reason why no requests had been made.

Those 14 practices which did have experience of providing medical information under the pilot arrangements reported collection of between two and 50 sets of records by the time of the research interview.

### 2.2.1 The impact on GPs

There was mixed evidence of any impact felt directly by GPs. Some said they had noticed no impact. In terms of their overall administrative work they felt two or three fewer IB113 forms per week could easily go unnoticed. However, such GPs readily acknowledged that their paperwork had been reduced if fewer IB113 forms had been passed to them for completion, even if they had not noticed this.

Reduction in workload had been noted by a GP who was a single practitioner in what was described as a deprived area, who reported normally receiving six or seven IB113 forms each week. These seemed a heavy burden and the practice was sometimes unable to meet requests for return in seven days. The reduction in IB113 requests was an improvement for this GP who hoped the arrangements would continue. A GP in a multi-partner practice in an area of relatively high employment had also noted a reduction in paperwork. This GP generally dealt with two IB113 forms each week, and each took 15 minutes to complete. For this practitioner the pilot arrangements took away an '*irritating and time-consuming administrative task*'. In the large multi-partner practices the work of completing

IB1 13 forms was shared out in different ways. Where there was a rota system and most of the weekly incoming IB1 13 work fell to one GP at a time, this could take more than two hours. Not surprisingly, a GP within such a practice had noticed a welcome reduction in this kind of work.

GPs reported no negative impacts for themselves of taking part in the pilot, and none knew of any negative impacts for patients. GPs in multi-partner practices thought they would have heard about any such outcome from their colleagues. There was some surprise that there had been little feedback from patients. Some GPs had expected patients to mention the new arrangements, but there was only one such report, of a patient who remarked that the benefit decision had been made more quickly under the pilot arrangements.

There was one report of the situation arising that had initially given some GPs concern, that of a patient coming for an appointment and repeat prescription while her notes were away. This was not reported as a problem however. The GP concerned knew the patient's circumstances; the prescription records were on the computer and it was not necessary to ask for immediate return of the notes.

GPs often said that their practice manager would have a fuller picture of the overall impact for the practice. It was expected that additional work had been created for the clerical and administrative staff, but not all GPs had yet discussed this with the staff. The experience and views of administrative staff in the practices is reported in the following section.

### 2.2.2 The administrative experience

Most practices in the study group, who had experience of dealing with requests for medical records under the pilot arrangements, had chosen to send the actual records, sometimes with additional print-outs from computerised records, depending on how far the practice had moved towards computerisation. The study group did include some practices which had opted to send photocopied notes and records, rather than the original documents, and one so-called 'paperless' practice which was sending only a print-out of electronic records.

In terms of administrative work required, this was variable depending partly on the number of requests coming to the practice, but mainly on whether practices were sending actual records or photocopies. The process was quickest and easiest for those practices sending actual case records. All these practices still maintained paper files for documents such as consultant letters and test results, and in some cases GPs' hand-written consulting notes. Practice managers or administrative staff found the paper files, and printed out whatever additional records were computerised.

A number of practices had introduced processes to avoid problems arising as a result of the notes being out of the surgery. Thus, in some practices, staff always checked to see if appointments or repeat prescriptions were due during the time the notes were likely to be away. Some practices routinely photocopied the last two consultation sheets, so that medical staff still had the most recent record if the patient needed attention. A number of practices had also introduced processes to help maintain patient confidentiality, for example, routinely removing notes made by non-medical counsellors and any reports made for solicitors or insurance companies. These additional individual processes were reported not to be time-consuming. It was often not realised by staff sending actual records that only those from the last five years were used in the medical assessment. When this was discussed, staff felt that separating notes from the last five years at the surgery would take extra time and be administratively cumbersome, requiring the need for new files or new filing spaces. They preferred to keep files together.

The general view of administrative staff, in practices which were sending actual records, was that this was relatively easy to manage and had not created problems for them. They felt the administrative

work was probably not taking more time than would otherwise be spent dealing with IB113 forms, in terms of retrieving patients' records, distribution of records and IB113 forms to GPs, monitoring progress, returning completed forms and refiling the records. It was not hard to fit the pilot arrangements into existing work schedules, which meant that staff could usually respond quickly.

Practices in this study group which had opted to send photocopies or print-outs, reported a rather different experience. The task of photocopying and dealing with the printing or scanning machines was generally dealt with by more junior staff. Some large practices employed part-time clerical staff just for photocopying or printing duties. The work for the pilot arrangements waited its turn for attention, along with requests from solicitors and insurance companies. Prioritising any photocopying work involved additional supervisory input, which was not always possible. For the staff doing the work, opening paper folders, removing staples and envelopes, photocopying, restapling and replacing material in correct order could be a lengthy business. In paperless offices, printing out individual sheets of scanned material could also be time-consuming. Clerical staff said dealing with one set of records usually took between 15 and 30 minutes, but could take up to one hour. Practices which were sending photocopies or print-outs knew that only five years' records were required and none were sending more than required.

Views varied about the length of notice given for collection. Two days was sufficient for practices sending actual records. This amount of notice was said to be insufficient by practices opting for photocopying or sending only print-outs, who said they needed four to six days to fit the task into normal work schedules.

The arrangements for collection and return of records generally worked well. No problems were reported in terms of delayed return, losing material or sending it back in an unsatisfactory condition. Practices were satisfied with the courier service, whose staff telephoned in advance of arrival, dealt courteously and appropriately with reception staff and kept a low profile in the surgery waiting area and car park. One practice which had arrangements for collection and delivery at two sites had wondered initially whether this would lead to confusions but was pleased with the efficiency of the courier service.

Experience of the work involved in implementing the pilot arrangements led to the view among some practice managers that the honorarium of £20 for sending photocopied records was insufficient. This amount was compared with £50 received as the minimum for photocopying records for private medical insurance purposes. It was known that the payments for participating practices were to be made only at the end of the pilot period, but there was some irritation that only through requests for payment had some practices learned that the pilot period had been extended from the original date.

## 2.3 Emerging views on pilot arrangements

Views on the pilot arrangements sometimes changed during the research interviews. During their interview some people gained apparently new information about the purpose of the pilot and the way that medical evidence was dealt with in determining benefit claims, and some misunderstandings were cleared up. Such new information influenced the reflections of the GPs and administrative staff on their experience of the pilot arrangements. One GP discovered during the research interview that, contrary to his initial expectations and preferences, actual records were leaving the practice.

Overall views on the new arrangements also depended on what people felt about the usual process of completion of the IB113 form. This section thus starts with a summary of GPs' views on dealing with IB113 forms.



### 2.3.1 GPs' views on the IB113 form

The IB113 asks the GP to provide factual information to the DWP medical officer (approved doctor) on the named incapacity benefit claimant. Payment for this work is included in GPs' overall NHS remuneration.

The general view among participating and non-participating GPs was that currently there were problems in seeking medical evidence to determine IB claims using the IB113. Filling in the form could be time-consuming. Generally, GPs said the form took about 15 minutes; those who said they liked to do this work '*properly*' said it could take 30 minutes to look at the records, decide what to write and fill in the form. Keeping abreast of the IB113 work sometimes meant taking the forms home to deal with in private time. One way of saving time was for nursing or administrative staff to fill in parts of the IB113 from patients' records. No GP interviewed said that they sometimes did not return the IB113 forms, but some with strong negative views about this work said they spent as little time on it as possible, and this could be just a few minutes for each form.

A view often expressed was that some of the questions asked on the IB113 were hard to answer, such as 'effects of the medical conditions on daily living'. GPs were irritated to be asked for information which they did not know. Some were concerned, however, that patients might be penalised by their answering 'don't know' or leaving blank spaces. Care was needed in providing answers on the IB113 in case the patient went to appeal and challenged what the GP had written. One way of dealing with this was to discuss with the patient how to fill in the form, but this was unusual and created even more work.

On the other hand, GPs who did know something about the patient's daily activities felt they were not always objective, because they tended naturally to act as '*advocates*' for their patients. It could be hard both to be fair to their patient and meet their responsibilities to the state. Some said that personal views inevitably crept in, such that an IB113 completed for a patient thought to be a '*genuine case*' was likely to contain information phrased in ways that might support the claim. On the other hand, when a patient was thought better able to do some work, the IB113 form was likely to contain only essential factual information set out succinctly. Some GPs saw the opportunity to influence the benefit decision as a result of what they wrote on the IB113 form as an advantage.

Some GPs felt their involvement in benefit decisions, by providing medical evidence on forms such as IB113, affected relationships with some patients who were angry when their claim for benefit was disallowed.

Different views among GPs on a number of the above issues contributed to a wide range of attitudes towards their provision of medical information on the IB113 forms. At one end of the spectrum were GPs who saw their work on benefit forms as part of their commitment to their patients and tried to be fair and accurate, sometimes despite insufficient time or irritation with the questions. At the other end were GPs who felt that they were not the appropriate people to ask for the information required, said they did not prioritise this work and sometimes did not take it very seriously.

### 2.3.2 Advantages and disadvantages of using GP records

Drawing on both their own experience and the discussion during the research interviews, GPs and practice staff who had taken part in the pilot weighed up the advantages and disadvantages.

The GP records were generally felt to provide fuller, more comprehensive information. This was likely to serve patients' interests better and lead to fairer decisions about benefits. In turn, the GP saved some time to spend on work which some felt more appropriate. A further advantage was that the new arrangements increased the distance between the GP and decisions made about entitlement, and thus reduced some potential for problems developing in the relationships with patients.



Disadvantages perceived by some practices sending photocopied material were that this created considerable additional administrative work, with insufficient remuneration under current arrangements.

There remained some concerns about releasing to third parties some kinds of sensitive information which was recorded in some patients' notes, for example information about social or marital problems, and convictions. This was linked to continuing concern about the level of patient understanding about material in full GP records and whether patients really understood what they were agreeing to. There was also continuing concern among both participant and non-participant GPs about the low quality of some GP case notes and records, especially from locums. Some hand written consultation notes were believed to be generally illegible.

As we might expect, non-participating GPs tended to continue to emphasise their concerns and the disadvantages they perceived. By the end of the research interview there was sometimes a reduction in concerns initially reported about issues to do with collection and return, as a result of greater understanding of options for transferring information. A request for records for the last two years might have led one non-participant GP to consider taking part more favourably, because recent records and notes were computerised. Other GPs, however, both participant and non-participant, felt a two-year period for assessment would be insufficient. They said that some conditions had long histories and this had a bearing on capacity for work.

When GPs, maintaining strong negative views about the pilot arrangements, were asked whether anything might change their mind, suggestions made included:

- evidence of better benefit decisions, at realistic cost for the Exchequer;
- evidence that patients wanted the new arrangements;
- specific written consent from patients (comparable to those prepared by solicitors);
- reduction of length of the period for which records were required to two years (thus enabling wholly electronic transfer procedure).

## 2.4 Summary

The pilot arrangements had been welcomed by GPs who saw opportunities for saving time and shedding an administrative chore, and a procedure likely to lead to a more balanced picture for benefits decisions, or at least no worse an assessment of their patient. GPs who had declined to take part had concerns about confidentiality, whether patients understood the implications of consenting to the procedure, and saw risks in loss of or damage to their records and not having continuous access in the surgery. Practices taking part in the pilot arrangements shared some of these concerns, but had resolved difficulties. Some had sought more information about how the records would be handled, and some had developed their own procedures to minimise practical risks or inconveniences. Practice managers were often of key importance in decisions made about participation in the pilot.

Not all GPs taking part had noticed any impact. Those who did were GPs practising on their own, GPs in areas of social disadvantage and those who tended to spend longer time in filling in the IB113 forms. The administrative and clerical staff with day-to-day responsibility for implementing the new arrangements had mixed views on the impact of the pilot. Practices sending actual records had found the process fairly quick and easy and no problems had arisen. In practices sending photocopied records and print-out from wholly computerised records, the additional work required was time-consuming and could be hard to fit into existing work schedules. As a result, it was not always possible to meet time requirements, and the payment was felt insufficient.

There was some evidence that GPs whose strong negative views had led to non-participation, might view the pilot arrangements more favourably with greater understanding about how the records were handled. Concerns remained, however, about confidentiality and informed consent.



## 3 Views and experiences of incapacity benefits claimants

This chapter presents views and experiences of the pilot arrangements of incapacity benefits claimants in the Sheffield and Rotherham area. The first two parts of the chapter explain what people understood about the pilot and why they decided to take part or not. Section 3.3 presents findings about people's general awareness of, and interest in, the process of medical assessment. Section 3.4 explains how they felt about their GPs, what they thought their medical records contained, and views on medical examinations. This sets the context for discussion of perceived advantages and disadvantages of the pilot arrangements, the subject of Section 3.5. The last part of this chapter presents claimants' overall views of the pilot. Appendix A explains the selection of the 32 claimants, whose views were sought for this part of the research, and provides a summary of their main characteristics. Twenty-two were recruited as participants in the pilot, and ten as non-participants.

### 3.1 Taking part in the pilot

The main source of information about the pilot was the DWP explanatory leaflet sent with the incapacity benefit claim form or the IB50 questionnaire. The leaflet included a telephone number for more information. People were given the option to opt out of the pilot by ticking a box on their claim form if they did not want DWP to have access to their case notes. People who submitted their claim form before the pilot started, and who were not required to fill in an IB50 questionnaire, were sent an explanatory letter (PEG1), and the opportunity to opt in.

#### 3.1.1 Awareness of the pilot

Although incapacity benefits claimants were recruited to the research as pilot participants or non-participants, at the start of their research interview not everybody was aware of their relationship to the pilot. The letters inviting people to be interviewed and the researchers' introductions served as reminders, but not everybody recruited as participants understood they were taking part and some recruited as non-participants believed their claim was being dealt with under new arrangements. Even after prompting there remained a small group of people who appeared to have no prior knowledge of the pilot arrangements, and were thus unable to discuss decisions about taking part.

Those who remembered they were in some form of incapacity benefits '*experiment*' knew that they had given permission. Not all such people could now remember what the pilot involved, but most who remembered giving permission thought they had understood at the time.

Some people remembered generally that the pilot was about medical records, or going further into their medical details. Non-participants retained less understanding about the pilot than people who had agreed to take part, as we might expect. Those people who had retained clear understanding that the new arrangements involved DWP looking directly at the medical records held by their GP included men and women in different age groups, and people recruited as new claimants and re-referrals.

### 3.1.2 Sources of information about the pilot

Few people could remember receiving a leaflet about the pilot; there were more frequent mentions of '*a letter*'. It was frustrating when the letter did not enclose the leaflet to which it referred, as some people reported.

Telephoning for more information had not worked well for those who had tried this. People who had sought information in this way said that staff seemed poorly informed. (We do not know whether such people used the advertised helpline or telephoned local DWP offices.)

Written information could be important; some people read this carefully and thought it was useful. Those who had clearest recollection of reading about the pilot and considering the new arrangements were existing claimants being re-referred for a PCA who agreed to take part. We might expect that some people who already had experience of the medical assessment procedures would be particularly interested in the idea that things might be done in different ways. Among the new claimants, not everybody who could remember receiving written information had looked at it carefully. Knowing their medical records would be used in the assessment for benefit could be all the information needed to decide whether to take part.

Those who remembered making a decision about taking part had known that participation was voluntary, although we see in the next section that some people thought refusal would attract attention. Nobody remembered giving thought to whether their GP was taking part in the pilot, but people were interested in this issue when the researcher raised it. There was some surprise that GPs could also choose whether to take part. Some people thought that if claimants wanted to take part in the new arrangements their GPs should be required to participate.

## 3.2 Deciding whether to participate

As explained, people did not need full understanding of the details of the pilot in order to agree to take part.

Reasons reported as influencing agreement to take part included:

- hoping to avoid a medical examination;
- hoping for quicker and easier administration;
- believing that DWP would be suspicious of people declining to take part;
- welcoming an opportunity to '*show willing*';
- having '*nothing to hide*' and thus no reason to decline;
- believing a '*full picture*' from medical records would help distinguish genuine and fraudulent claimants;

- believing medical records would help educate DWP staff about mental illness;
- believing that advances in society required readiness to try new things;
- general support for policy pilots and public consultation.

These reasons for taking part fall generally into two groups: possible direct consequences for themselves and other claimants, and perceptions of the pilot arrangements as a generally better way of doing things.

Hoping to avoid being asked to go for a medical examination could be a powerful influence. Previous bad experiences at medical examinations meant that some people did not want to undergo another. Others who feared being asked to go for a medical included people with mental illnesses which made it hard for them to leave home or talk to strangers. They believed such problems might be interpreted as non-cooperation, leading to loss of benefits. Their hope was that their medical records would provide all the information required for DWP to make a decision without calling them for a medical examination.

Apart from the medical examination, some people thought that the administrative process would be generally simpler and quicker under the pilot arrangements. Not having to go to the GP for a Med4 was attractive. Others did not identify specific elements in the claiming process but had a general feeling that it might all be easier under the pilot arrangements, especially people who had previous bad experiences of administrative muddle and delay.

Another reason for taking part was belief that DWP would be suspicious of people who opted out and it could seem better not to attract attention. This had led to some people feeling some pressure in agreeing to take part. On the other hand, some people welcomed an opportunity to demonstrate their readiness to take part. People with different kinds of mental illness said they wanted to be seen to be ready to cooperate with DWP to reduce the kind of stereotyped stigma and suspicion attached to their illness.

Just having '*nothing to hide*' and, thus, no reason not to take part could be sufficient to agree to participate. Some people had not bothered to read all the information or think much about it; some who had been more interested saw no particular consequences for themselves. There then seemed no reason not to give permission, although one person observed that the way agreement was sought appeared designed to make it easier for people to agree to take part than not.

Perceptions of the pilot arrangements as a generally better way of doing things included the belief, often expressed, that the evidence in medical records would help to distinguish 'genuine' from 'fraudulent' claimants. Another view was that if more DWP staff looked at real medical records, they would understand mental illness better. Some people observed that society would not move forward unless people were prepared to try new things, and one person in particular strongly supported the idea of pilots and trials with public consultation, as a good way for a democratic government to develop policy.

The strength of such beliefs and feelings varied considerably between individual people. A person who feared being asked to go for a medical examination and was confident that her medical records showed she could not work was making a strong positive choice in agreeing to take part in the pilot. By contrast, some people could think of no reason for or against participation and attached little importance to the matter.

Few people were interviewed who could tell the researchers why they had decided not to take part in the pilot. Ten people were recruited to the research as pilot non-participants, some of these did not

remember being invited to take part, as explained previously, and one person believed he had given his permission and was taking part. For some people it appeared that the decision not to participate was effectively made by third parties. People making a new claim, who had received help with form filling from advice workers or hospital staff, said their adviser must have decided against their taking part, although they could not remember having discussed this. One person who could remember talking about whether or not to take part asked his GP about it. He said that the GP suggested it might be easier to send the Med4, and since he was already at the surgery this would be no trouble.

Among the small number of people who had decided themselves that they preferred not to take part, the following factors were reported as influential:

- objections on grounds of confidentiality;
- mistrust of DWP use of information in GP records;
- belief that GPs would get '*blamed*' if patients lost benefits;
- perception of administrative problems;
- belief that participation would result in additional demands on claimants.

There was some objection to the pilot on the basis that GP notes and records should be confidential between doctor and patient and not available to other people. A person expecting his GP records to be used in a law suit thought they should not also be used for other purposes. Linked to issues of confidentiality was some mistrust that DWP would use the information in the notes solely for the purposes proposed, but would take the opportunity to look for reasons for denying people benefits. Some thought that people who were not satisfied with the outcome of their assessment would be likely to blame their GP, if the decision was based on the GP's records. Administrative problems perceived included extra work for office staff in the surgery and possibility of loss of the records while they were out of the surgery. There was some feeling that agreeing to take part would bring additional demands on claimants and unwanted attention in some way, perhaps additional callers at home, or extra requests to visit Sheffield offices.

It is important to say again that these reasons for not taking part came from only a small group of people. The person who argued most strongly against the pilot, drawing on several of the above issues, had actually been recruited to the research on the basis that he was a pilot participant and it was not clear to the researcher what his status was in relation to the pilot.

As we report below, some of the non-participants subsequently told the researcher that their decision might have been different had they known more, or understood correctly, about the pilot arrangements.

### 3.3 Awareness and understanding of the process

In order to explore people's understanding of the process of assessment, the researchers asked what they thought happened the last time they had dealings with DWP about their incapacity benefit. For the participants, this was the claim made under pilot arrangements; for non-participants, the claim made under the usual arrangements.

Not everybody was interested in what happened. Those who made suggestions thought staff would look at what they themselves had written on the forms, and decide whether to seek some medical information as proof that they were entitled. Only rarely did people mention a contributions or income check. The kind of medical information DWP needed in order to decide entitlement was

expected to include details about past health, history of illness and treatment, current medical circumstances and the effects on their daily lives.

As to where DWP was likely to seek such information, most who had views suggested the GP. People who had been in hospital, were receiving out-patient or psychiatric care, attending pain clinics, diabetic clinics, drug rehabilitation centres or eye hospitals felt that the most appropriate medical information for the DWP was held by consultants or other health specialists. Some felt that DWP would write to their consultant, but not everybody was confident that this was part of the process. Wondering if DWP might deal with their claim solely on the basis of medical information supplied by a GP could be a concern. A small group of people, participants and non-participants, thought that the GP was not approached again for the incapacity benefit claim, but that the primary medical evidence was the number and contents of sickness certificates issued.

Other suggestions of possible sources of information included occupational health personnel or managers at work. There was also a belief that DWP would draw on medical information already supplied, for example looking across previous sick notes, or reports for claims for industrial injuries benefits and allowances.

Views varied as to which DWP staff had responsibility for collecting the information and making decisions and how this happened. A few people mentioned the points system or '*formula*' but this was not well understood. Some suggested decisions about entitlement were made by a '*panel*', '*board*' or '*jury*', expected to include doctors, DWP personnel, or possibly solicitors. Medical examinations were generally thought to be part of the overall process, but few had a full picture of how the medical fitted in. It was generally thought that assessment '*panels*' and medical examinations were located at centralised offices, and suggestions included Sheffield, New castle and Leeds. As we might expect, long-term incapacity benefits recipients and people whose relatives also had histories of claiming incapacity/invalidity benefits had the best grasp on the overall procedures.

Pilot participants, who had previously been assessed under pre-trial arrangements in the current or previous claiming spell, perceived few differences in the processes experienced thus far, although some had noted not having to get a Med4.

### 3.4 Relationships with GPs, perceptions of medical records, and views on medical examinations

We would expect claimants' views of the new arrangements to depend partly on their relationship with their GP and how carefully they expected the GP to fill in benefit forms about them. Views might also depend on what people thought GP records contained and how medical examinations fitted into assessments. This part of the chapter presents findings on these issues, to inform understanding of claimants' overall views about the pilot arrangements.

#### 3.4.1 Relationships with GPs

As we might expect, there was wide variation in people's reported relationships with their GPs, in terms of: length of the relationship; frequency of and reason for contacts; continuity of contact in multi-partner practices; and satisfaction with the care provided.

At one end of the spectrum were people who said they went to the surgery only for repeat prescriptions, rarely saw the same doctor twice, and did not rate the GPs very highly. At the other end of the spectrum were people who visited, at least once a month, a respected GP whom they had known from childhood. Similarly, there was wide variation in people's expectations and experiences



of discussing benefits and work with the GP; their confidence in the quality of the GP's records and general record keeping; and their own assessment of their GP's commitment to careful reporting on benefit forms.

### 3.4.2 Perceptions of medical records

Everybody had seen their GP making notes during consultations, either handwritten or on the computer, and most people had seen a 'file' or 'folder' for storage of notes and other items about them. Nobody in the study mentioned ever having asked to see notes kept about them.

There was variable knowledge about, and interest in, what else might be in the file. Suggestions included correspondence between the GP and hospital consultants including details of investigations, operations, treatment and progress; results of tests done at the surgery and in hospital; X-rays; prescription records; appointments with psychiatrists and counsellors, and records of work absence. Some people wondered how paper records were linked up with computer records in the surgery, or whether the records and notes were ever weeded out, to make space by getting rid of unwanted information.

While some were confident that their medical records held by the GP went back to their birth and were transferred as they moved home or changed their doctor, others were less sure that their current GP had a full historical record.

### 3.4.3 Views on medical examinations

Although new claimants had no recent experience of a medical examination for incapacity benefit some had been for medicals in previous claiming spells. Most recruited as re-referrals remembered a previous medical for Incapacity or Invalidity Benefit. In addition, some people recalled medical examinations for Disability Living Allowance or industrial injuries benefits. Some had clear memories of what parents or spouses had told them about their medical examinations. As expected from previous research, people drew on all such experiences and accounts when they discussed the place of medical examinations in assessments for incapacity benefits.

There was a wide range of feelings about previous personal experiences of medical examinations, linked to benefit outcomes and how people felt the examining doctor had treated them. Practical problems were also mentioned including the difficulty of the journey and budgeting in advance for the cost of travel. This study was not designed to explore fully respondents' experiences of medical examinations. Rather, the focus was on people's perceptions of how a medical examination fitted into the assessment for benefit, and the role of any medical information about claimants provided for the examining doctor.

There was a widespread belief that everybody receiving incapacity benefit was eventually asked to go for a medical examination. Others thought there was a selective process in which some people were more likely to be asked to attend, although the criteria involved were not clear. A few people suggested that the requirement for a medical was linked to the length of the claim in some way. Suggestions here were '*so many weeks after claiming*' and then '*every 12 months*', or just simply when people have been off work for a long time, or '*seemed to be getting better*'.

There was widespread acceptance of the importance of medical examinations in the assessment of incapacity benefit and support for the principle that everybody should have a medical examination eventually. Underlying this was a belief that deciding whether a person's condition prevented them from working could only be made properly by seeing the person and talking to them about '*what was wrong*' and how they felt. Even people who were anxious about being asked to go for a medical, and

people who had previously had bad experiences and disappointing outcomes, could support in principle the idea of a medical as an important part of the decision process.

There was also belief that a medical examination would help identify people making fraudulent claims.

Those who felt that medical examinations would be unhelpful for their own claims included people with symptoms of mental illness which would prevent them from going to an appointment, or communicating with the doctor when they got there, and who feared subsequent loss of benefit. A small group of people thought that a short medical was insufficient for an unfamiliar doctor to assess their condition, especially when this varied, or was complex.

The need to conduct separate medical examinations for different state benefits such as Incapacity Benefit and Industrial Injuries Benefit was believed to be a waste of time and resources.

There was general support for the examining doctor to have available as much information about the claimant as possible, and this included information from the person's GP. Those who believed that the fullest picture of their condition and its effects lay with their hospital consultants felt it was important for the examining doctor to have this kind of information.

When asked directly if it would be better for the examining doctor to see their actual GP records or have the GP's written opinions, most people opted for the actual records on the basis that these would provide the fullest picture, and that medicals would be shorter and more fitting if the doctor had full information in advance. There was, however, some scepticism among people who had already had an incapacity benefit medical examination, that the examining doctor would actually read through lots of notes. Some were critical of what they had experienced as short examinations by doctors who appeared to know little about them.

A person who would prefer the examining doctor to read information from the GP written on a standard form rather than the GP records, emphasised the need for a personal opinion from medical personnel who knew her history and current situation.

### 3.5 Advantages and disadvantages of the pilot arrangements

In order to get informed opinions about the pilot arrangements, towards the end of the interview the researcher summarised the main differences between usual arrangements for collecting medical evidence and the arrangements in the pilot. The emphasis was on the basic difference between asking the GP to send medical information by writing on a form and asking the GP to send notes and records. This served to confirm people's understanding, correct misapprehensions or increase their knowledge. For those who had little prior understanding or less interest in procedures, it could be hard to absorb new information of this kind during the interview, and misunderstandings and confusions remained among some of the respondents. It is important to remember this in considering claimants' overall views on the new arrangements.

Some people saw only advantages, or expressed only negative views. Others identified advantages but expressed some concerns or qualified their comments with reference to possible disadvantages.

### 3.5.1 Positive views

Claimants in both the participant and non-participant groups expressed positive views about the pilot arrangements. There was no systematic difference in the views of new and re-referred claimants. Advantages identified spontaneously included anticipated effects for themselves or other claimants and for the DWP, and effects for GPs.

The advantages for claimants and the DWP were that staff making decisions about benefits would have a fuller picture of the claimant's condition and its effects. There would be less danger of GPs omitting essential information, and important information from hospitals and consultants would all be available. The GP records would demonstrate change in someone's condition over time, which might be important.

With a '*full picture*' and more '*proof*' from the GP records, benefits staff would be better able to make the right decisions. This meant that they (the claimants themselves) would be more likely to be identified as properly entitled to incapacity benefit, and there would be no doubt about how ill they were (this latter point was emphasised especially by people with mental illness). The full picture from the GP records was also more likely to identify people making fraudulent claims (other people who were able to work) and would prevent claims being decided on the basis of information written by (other) over-sympathetic GPs.

Further advantages for claimants were that there would be no need for a GP appointment just to get a Med4. Fewer medical examinations would be needed, thus there would be fewer unnecessary demands on claimants and, some thought, less expense for DWP. If a medical was required, people would be asked fewer and more relevant questions because the examining doctor would already have full medical information.

Advantages were perceived for GPs in terms of a reduction in the work involved in getting information from the records or computer, remembering the patient and thinking what to write, and filling in forms. Less benefits work for GPs would mean more time available to spend with patients.

### 3.5.2 Negative views

Again, people in both participant and non-participant groups expressed some negative views about the pilot arrangements, and potential disadvantages were identified for claimants and the DWP, and GPs.

Issues were raised about confidentiality. There were concerns about who would have access to medical notes and records while they were out of the surgery. Not everybody trusted the DWP to use the records only for purposes of incapacity benefits.

Contrary to those who believed that the GP notes would provide the '*full picture*', some claimants thought that the GP records did not always reflect the full impact of a person's condition. Some matters were discussed with, and known by, the GP but not recorded (mentioned by people with mental health problems). Thus, in some situations, the GP would be able to provide more relevant information on the IB113 form than would be found in the records. Using medical information from GP records did not address the problem perceived by some who thought that information relevant to their claim was held by psychiatrists or consultants, and was not all in their GP records. People who discussed their condition mainly with counsellors or advice workers, or were dealing with their condition through self-help groups also thought that the relevant information for their incapacity benefit claim was not in their GP records. One person made the point that if DWP relied on GP records, those people who received all their support and help through self-help groups and alternative

therapies, and were trying not to rely on medication, only visited their GP for benefits certification. It might be easy for a third party looking at the GP records to interpret their lack of GP consultation and treatment as evidence that they were not ill.

One claimant who was well informed about the pilot arrangements felt that a period of five years was not long enough for seeking relevant medical information. Some conditions fluctuated, or developed in response to other earlier conditions, and this affected people's capacity for work.

One view was that neither the pilot arrangements nor the IB113 procedure addressed the problem perceived that some (other) people did not tell the truth to their GP.

There were some anxieties that even if the GP records were potentially a better source of information than information provided on the IB113 forms, DWP staff might not use it properly, for example using only information which would disallow a claim. One suggestion was that it would be time-consuming to examine properly a long medical record. If some benefits staff had time only to quickly scan the records, some relevant information could be missed. Another suggestion was that medical examinations would be dominated by the doctor reading GP records, leaving insufficient time to examine or talk to the claimant.

The pilot arrangements appeared to some claimants to introduce new forms of bureaucracy and the possibility of greater expense overall. One person suggested that if the pilot arrangements did lead to extra expense for DWP, charges might be introduced for claimants. If the GP records did provide better information for the DWP, this would mean more disallowances and more appeals. This could undermine GP/patient relationships, and more appeals would be a disadvantage for DWP.

Some claimants saw other disadvantages for GPs in extra work and expense in transferring the notes and records and the possibility of them being lost during transfer and use. There could be problems if records were not in the surgery when the patient needed treatment, and one person reported this experience herself. The point was made that some GPs just might not like their own notes being looked at in this new way.

As people weighed up advantages of the new arrangements against potential negative effects, some emphasised the importance of the quality of the information supplied to DWP, as well as the relevance. Only one person thought there would be any impact on their own relationship with their GP, but there were suggestions that it would be important for GPs to know in advance that claimants had given their consent to records being used in this way.

Views varied as to whether the new arrangements would be quicker, overall. Having less paperwork would save GPs' time, but the time input in the surgery might just be shifted onto administrative staff who had to deal with practicalities. It was also thought likely that staff using the medical information would need more time under the new arrangements, reading through all the different pieces of information, letters, tests and records. As a result, some people thought that it might take longer to reach a decision.

It was people who were recruited as pilot participants, who had been re-referred, who made the most sophisticated analysis of the advantages and disadvantages. They weighed up possible positive and negative impacts, seeing a number of arguments on both sides, sometimes illustrated from their own experience within and before the pilot.

## 3.6 Overall views of the trial

Before summarising claimants' overall views about the pilot it is important to remember that even at the end of their research interview some people still had little understanding of the medical assessment process, confusions or big gaps in their knowledge. Some people said they were just not much interested. What is presented here are the main patterns which emerged, and the issues of particular interest for policy makers. Some of the views expressed come, however, from relatively small numbers of people.

### 3.6.1 On taking part

By the end of the interview, most people recruited as pilot participants, including those who initially had not realised their own assessment was being dealt with under new arrangements, said they were content to have been included. There was a feeling that it was better to test new arrangements before introducing them for everybody, and that somebody always had to be '*the guinea pig*'. Some wished they had understood the process better, however.

Only one person in the participant group said if she had fully understood that only the last five years of records were examined she would not have taken part. She believed that a full picture of whether she could work depended on looking at her records and considering her condition over a longer time period.

Most people recruited as non-participants appeared more positive about the pilot arrangements at the end of the interview than at the beginning. Greater understanding about what was involved in the pilot helped to address some of their initial concerns or uncertainties. It was not unusual for non-participants to say that they would have been more likely to take part if they had understood more at the time.

### 3.6.2 As a technique for testing policy

There was some interest when people learned that the pilot was only taking place locally. Some were pleased that they had had an opportunity to help find out whether a new idea worked.

Learning from the researchers that GPs had been able to choose whether to take part drew some disapproval, as described earlier. It was considered wrong that some people, who might have wanted their claim dealt with under pilot arrangements, had been denied the opportunity.

### 3.6.3 On implementing the pilot arrangements nationally

By the end of the interviews, most people felt that it would be '*a good idea*' or '*all right*' to introduce the new arrangements nationally, although they thought some other claimants would not like it, especially people who felt it was invading privacy and those who were subsequently disallowed benefit. Claimants thought that some GPs were likely to be resistant, not wanting other people to look so directly at how they worked.

Some pointed out their views might well change when they learned the outcome of their recent assessment. Being disallowed benefit would tend to strengthen negative feelings about whichever arrangements had been used. The person who wished she had not taken part in the pilot said that if benefit was refused she would certainly appeal on the basis of being in a trial about which, she felt, insufficient information had been provided. Strong feelings against extension of the pilot arrangements also came from a man who thought that it would '*cause trouble*' by leading to more appeals and poorer relationships between GPs and patients.

Some people were puzzled about how the issue of individual consent would be dealt with if the pilot arrangements were introduced on a national basis or if they became compulsory. People emphasised the importance of ensuring confidentiality in dealing with the medical records and notes if the new arrangements were to be generally implemented. Speedy return and careful handling of notes taken from the surgery would be essential.

### 3.7 Summary

Not everybody in the claimant study group was aware of their relationship with the pilot. By the end of the research interviews some still had gaps in their understanding of the general medical assessment process, and the pilot arrangements.

Those who remembered agreeing to take part in the pilot were influenced by possible consequences for themselves, such as avoiding a medical examination, or not wanting to attract attention by declining to take part. Some liked the idea that seeing the medical records would help DWP distinguish genuine claimants. Only a small group of people remembered deciding not to take part, usually because of concerns about how the GP records would be used, or administrative problems perceived for GPs and themselves.

Claimants generally understood that GP records included consultation notes and records of prescriptions, and some also knew that letters from consultants and results of hospital tests were included. There was wide variation in claimants' reported relationships with their GPs, and their expectations of their GP's approach to providing information for benefits purposes, both of which could influence views of the pilot arrangements.

Both advantages and disadvantages in the pilot arrangements were perceived for claimants, DWP and GPs. Nearly all those who had taken part were content to have been included, and most of those recruited as non-participants appeared more positive about the pilot arrangements at the end of the research interview, when they understood more, than at the beginning. Most of those interviewed, who had a view as to whether the pilot arrangements should be introduced on a national basis, felt positively about this. These views might change when people received their decision about benefit entitlement.



## 4 Administering the pilot arrangements

### 4.1 Implementation in Jobcentre Plus

Within Jobcentre Plus, staff in the medical administration teams dealt with claims processed under the pilot arrangements alongside incapacity benefits claims being dealt with in the usual way. Group discussions with three teams of administrative staff, nearly 12 months after the introduction of the pilot, provided information about the effect of the pilot on the work of the processing staff, and further perspectives on the impact of the pilot on claimants and their advisers. Details of recruitment to, and conduct of, the group discussions are in Appendix A.

Most of the discussion with staff was concerned with differences in practice in processing claims under the pilot arrangements in comparison with usual ways of working, and the effect of these changes. As we might expect in the introduction of a new way of working, some problems did arise. Understanding what was happening provides useful pointers to ways of avoiding such problems should the pilot arrangements be introduced elsewhere. Drawing on their direct practical experience, staff gave their views on the main strengths and weaknesses of the pilot arrangements.

#### 4.1.1 The impact on working practices

Normally, the administrative work required in processing Personal Capability Assessments in Jobcentre Plus is largely computer driven. Staff work in response to what are called 'BF prompts' (Brought Forward), which indicate appropriate processing stages and time limits for individual claims. Staff use the computer to issue standard letters and forms, manage the administrative flows to and from decision makers and Medical Services, and, depending on outcome, withdraw benefit. Some reminder letters are issued automatically to claimants from whom a response is required, according to stages reached and pre-set time limits. It was decided that the pilot would rely on clerical procedures, and that any decision to extend it more widely would require consideration of supporting IT changes. No new computer programmes were inserted for processing and managing claims dealt with under the pilot arrangements.

Jobcentre Plus staff and the pilot project knew when the pilot was set up that the reliance on clerical procedures would mean that they would have to take more decisions themselves about processing, and do more clerical and manual work in dealing with claims under the pilot arrangements. They explained the impact of this. First, staff had to decide whether to deal with the medical assessment



under the usual arrangements or the pilot. This meant checking first whether that person's GP was taking part in the pilot. Staff had lists of GPs and practices which indicated which doctors were taking part in the pilot. It took some time to search through these lists, which were re-issued quite frequently because, staff understood, some GPs changed their minds about participation during the pilot. Finding the claimant's GP was not always straightforward; for example, if patients had seen locums or changed their address or if GP practices operated from more than one surgery. It was sometimes necessary to telephone surgeries, and this could mean having to explain the pilot to practice staff. Staff thought there was the potential for some errors in matching claimants to GPs, and deciding whether claimants were pilot participants or not. Claimants could change between the categories of participant and non-participant during processing, for example, if they changed their GP or changed their mind. Which category claimants belonged to was not always clear, and additional checks and telephone calls were required in order to make the right decisions.

Additional confusions arose when instructions changed, early in the pilot. For example re-referral PCA cases were introduced two months into the pilot, requiring some re-learning of procedures. A frustration which remained throughout the pilot was that there was no indication to staff of what changes had been made when lists of participating/non-participating GPs were re-issued, so they had to search through carefully themselves each time they received a new list.

When claimants were identified as potential participants, staff first had to adjust their computer programme so that the normal prompts were overridden, and then set new BF prompts to guide the process. They estimated that this took four or five times as long as setting prompts under the usual arrangements. The decision was then made, as usual, whether to deal with the claimant as a person with a mental illness or terminal illness who was potentially exempt. Under usual arrangements, and on behalf of the approved doctor (medical officer), they would issue the IB1 13 to the person's GP, for return to the approved doctor. Under the pilot arrangements, they sent the claimant's details and the GP's reference number by fax to Medical Services, a new component in the process.

In addition to the cases described above, new claimants who were potentially exempt, and those returned with advice from an approved doctor that the claimant was not exempt, were people who were potentially exempt but who had started their claim before the pilot started. For these people, staff issued a hand written PEG1 form with explanatory information about the pilot, seeking claimant agreement to take part. If positive replies were received, the consent was copied and sent to Medical Services by fax, with a tracking form SB1. Replies from claimants could take a long time, however, and sometimes came after the time limits had expired and the case was already being dealt with under usual arrangements. Staff thought that some people with mental illness, and some people with drugs or alcohol problems took a particularly long time to deal with letters from the DWP. If they did receive a consent to participation from a person whose claim they had already started to deal with under usual arrangements they tried as far as possible to intervene in the process, for example, sending a covering letter to Medical Services. This again caused additional work.

Some people making new claims came into the pilot by indicating consent on the application form. The next stage for non-exempt participants was to send them an IB50P, the questionnaire for self-completion. This was the usual form IB50 with an additional explanation of the pilot, and another opportunity to opt out. When these forms were returned, some claimants already notified as pilot participants had opted out (and vice versa) and had to be recategorised, with covering notes sent to Medical Services.

In addition to the additional clerical and administrative work described above, staff explained that if pilot cases took some time to process, measures initially taken to override the usual system prompts began to produce 'action overdue' prompts and prompts to alert staff to time limits running out. As

a result, their 'prompt load' increased considerably, and required additional work. In one office which reported low staff levels and other problems during 2002 the pilot had increased backlogs of work and sometimes seemed like '*an ongoing struggle*', even with additional resources. In all offices, it had taken some time to get used to the new arrangements.

When staff were asked what they thought had been the effect of the pilot on decision making there was some doubt that the pilot had led to more paper-based exemptions or fewer medical examinations, as hoped, although relatively low numbers of participants meant that it was hard to see definite patterns. In one office, staff thought that the pilot arrangements had probably delayed decisions<sup>10</sup> for claimants as a result of the additional processing components and extended time limits.

### 4.1.2 Perspectives from claimants

Telephone enquiries about the pilot arrangements from claimants and their advisers provide useful perspectives on concerns and issues arising for people whose incapacity benefit was being dealt with during the pilot period.

Enquiries were sometimes made in response to receipt of the PEG1 or IB50P. Some people wanted to know what would happen to their GP records when they went from the surgery and how they would be used. There were concerns that records would be dealt with in confidence and with care, and either returned or that photocopies would be shredded. Staff said that some claimants were pleased to hear that information in their GP records would be available to people making decisions about benefits. This was reported especially from some people with mental illnesses and some people expecting to be asked to go to a medical examination who said that better and fuller information about their condition and its effect would be in their GP records.

Staff also received telephone calls from people who did not understand the PEG1 form, seeking guidance from staff about whether they should agree to take part. Staff tried to explain the pilot arrangements and what would be involved, but tried to avoid influencing decisions. Some people telephoned to let staff know how much they disagreed with the proposed arrangements. Later in the process, some participants telephoned to find out whether Med4 forms were still required, and to sort out other confusions. Altogether, processing staff received an increased number of telephone calls from claimants during the pilot, and some of these required sensitive handling. There were, however, very few enquiries from GP surgeries, benefits advisers or health/care professionals. Each team could remember only one or two such enquiries during the pilot period.

### 4.1.3 Strengths and weaknesses of the pilot

Staff had initially been interested in the pilot, and keen to take part effectively, although concerned about the lack of computer programme adjustments for implementation. There had been disappointment and some surprise at what seemed a relatively low number of GPs agreeing to take part.

In the office, immediate managers had been supportive of staff engaged on the pilot, and it was agreed that relaxation of performance targets during the pilot had been realistic. However, there was some feeling that staff had been left to find their way through problems by those who designed the pilot. It could have been helpful to have some 'project support'; for example, some meetings with staff in other offices, or project personnel who kept closely in touch with what was happening, and were available to discuss issues as they arose, especially in the early stages which were hard.

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<sup>10</sup> Delayed decisions do not automatically mean delayed benefit payments, as people receive benefit while waiting for a Personal Capability Assessment decision.

Looking back on the pilot, the main weaknesses perceived were:

- the lack of IT support, increasing clerical and manual workload;
- introduction of changes during the pilot, requiring re-learning and leading to some confusion;
- lack of overall support and information for staff running a pilot.

Requirements for both GP and claimant consent were not seen as weaknesses, but as factors which increased complexity, created extra administration and, in some cases, delays.

When asked about the strengths of the pilot arrangements, one view was that claimants would have no grounds for believing that their case had not been looked at thoroughly. There would be less chance of doctors conducting medical examinations without relevant information. This might lead to fewer telephone calls from angry claimants. There was some doubt that there would be much effect on the number of appeals, however, as many factors influenced whether people appealed against withdrawal of benefit.

On balance, it was thought better to have run a pilot than not, when considering a major change in procedure. An additional strength of the pilot was that there were now administrative staff who had key information and expertise if decisions were taken to introduce the new arrangements generally. Staff hoped that they would be consulted. They felt their views would be of great value, for example in providing advice on how to adapt the computer programme and how staff could be helped to learn the new process.

In all offices, the general view from Decision Makers was that the quality and detail of medical information extracted from GP notes and records, as seen in the case papers they were processing under the pilot arrangements, was higher in comparison with what was written on IB113 forms. If all GPs were required to cooperate; and if all claims were dealt with under these arrangements; and if there was requisite IT support staff thought medical assessments would be better. There remained some concern about whether all claimants would understand how their GP records were being used, and whether they would all agree with this. Running parallel processes, for claimants who did and did not agree to take part, would be far from ideal, however, and possibly unworkable.

## 4.2 Implementation in the Leeds Medical Services Centre

Within the Leeds Medical Services Centre administrative staff dealt with claims processed under the pilot arrangements and the usual arrangements. The team leader who oversaw this administrative work was interviewed about the impact of the pilot on the team's work, and approved doctors were also asked for their views on the workings of the pilot.

The Leeds Medical Services Centre is managed by SchlumbergerSema, a commercial company that, since 1998, has been contracted to provide the DWP and Jobcentre Plus with medical advice on state benefit claims.

### 4.2.1 Impact on working practices

The medical evidence pilot required a number of new administrative procedures to be introduced. Cases to be decided under the pilot arrangements were received from two of the participating Jobcentre Plus offices. These contained evidence that the claimant had consented to take part in the pilot. The case was first logged on a database specially created for the pilot. The database was used to track the progress of the case and to record information intended to assist SchlumbergerSema and

DWP in the evaluation of the pilot. The next task within the Medical Services Centre was to request the GP notes. This required a notification to be sent to the courier firm, which included the claimant's consent.

The task of the courier firm was to arrange collection of the claimant's record from the GP's surgery, scan the contents onto a CD, and deliver this to the Medical Services Centre. The target for achieving this turnaround of cases was set at ten days. It was reported that in most cases this target was met. Security of the CD was important. Deliveries from the courier firm were made directly to a secure, locked office to which access was restricted. In the Medical Services Centre the CD was then linked to the appropriate paper case file and allocated to one of the approved doctors, who took whatever action was required (i.e. made a decision about exemption, or carried out a scrutiny of the case).

These administrative procedures contrast with the usual arrangements for dealing with incapacity benefit claims. Here case files arrived from a Jobcentre Plus office and were allocated immediately to an approved doctor. Staff in the Jobcentre Plus office may already have requested an IB113 from the claimant's GP on behalf of the medical officer. If an IB113 report had been returned it was in the claimant's file. Under the pilot arrangements, therefore, there was an additional stage in the administration of claims, and one of the impacts of the pilot was that the time a case spent in the Medical Services Centre had increased in comparison with the usual arrangements.

Under the usual arrangements an approved doctor requiring further information from a GP about a claim had two main options. They could pass the case back to the administrative staff with instructions to send the GP an IB113 or they could complete a customised 'request for information' form (FRP2) containing specific questions about the claimant. The first of these options was rendered unnecessary under the pilot because all cases contained an SB2 form in place of the IB113. In principle, therefore, the pilot could be expected to produce a reduction in this kind of work for administrative staff. In practice, few such additional requests for IB113s are ever made and no actual reduction had been noticed.

It was reported that the flow of pilot cases had been very slow in the early months and had increased only gradually. At its peak, however, the flow had reached around 20 cases per day. By the time of the research interviews towards the end of the pilot, the rate had fallen to around four a day.

It was explained that as soon as a CD of a claimant's GP record had arrived in the Centre it was allocated to an approved doctor for action. Cases were not stockpiled until a predetermined number had been reached, nor were different types of case allocated to particular doctors. The aim was to process the claims as quickly as possible in order to meet internal targets and contractual requirements.

It was noted that the task of collecting and entering information about processing claims for monitoring and evaluation purposes had been an additional impact of the pilot. However, it was recognised that this work was linked to the design of the pilot and would not continue in the same form after its end.

## 4.2.2 Implications of the pilot

The pilot was reported to have created additional work for the administrative staff of the Leeds Medical Services Centre. This work was not in itself problematic. The systems that had been put in place to administer and monitor the pilot had worked well. In conjunction with the courier firm the supply and secure handling of the CDs of GP records had also worked well.

If the pilot was to be extended elsewhere, it was suggested that consideration could usefully be given to two particular aspects of the pilot arrangements. First, the additional work placed on Medical Services Centres in arranging collection of GP records and in handling them securely would have resource implications if this task remained with them in the future. Secondly, there was a perception that the requirement to send copies of claimants' consents to the courier firm added to the administrative burden in processing cases. There was, therefore, the potential of reducing this by designing different consent procedures based, perhaps, on some form of electronic transfer.

### 4.3 Summary

The pilot created extra administrative and clerical work for Jobcentre processing staff and the Medical Services Centre. The staff involved were interested in the project and committed to implementing the pilot arrangements efficiently. These staff have key information and expertise if decisions are taken to develop the new arrangements at a national level.

## 5 Using GP records in the administration of Incapacity Benefit

This chapter presents the experiences and views of approved doctors about the pilot arrangements and their usual methods for processing incapacity benefit claims. Approved doctors play a central part in both the use and production of medical information, and under the pilot arrangements are the only people to make direct use of the actual GP records supplied by the practice. The next chapter explores the use of medical information by Examining Medical Officers (EMOs) and by Jobcentre Plus decision makers.

For Incapacity Benefit claims, the role of the approved doctor encompasses the following:

- to advise a decision maker whether a claimant's medical condition or disability appears to meet the criteria for exemption from the Personal Capability Assessment (PCA);
- to advise a decision maker about a claimant's functional status in relation to the PCA on the paper evidence (the 'scrutiny' stage); and
- where required, to advise a decision maker about a claimant's functional status in relation to the PCA, following a face to face examination (the PCA examination).

Under the pilot, the approved doctor had the additional task of extracting relevant data from GP records to prepare an SB2 form (extract of GP records).

The SB2 information is subsequently used by an approved doctor as medical evidence to inform one or more of the above three advisory stages of the PCA process.

At the time of the research interviews, four approved doctors were carrying out these tasks. Two of these doctors also had experience of carrying out medical examinations for incapacity benefit claimants. All four approved doctors were interviewed for the research. Full details of the conduct of the interviews are in Appendix A.

Section 5.1 presents findings on the experience of the exemption stage of the process. Section 5.2 presents findings on the process of extracting information from GP records and views on the quality of GP records that approved doctors work with. Experiences of the scrutiny stage of the process are discussed in Section 5.3. The last part of this chapter presents the overall views of approved doctors about the pilot arrangements.

## 5.1 Extracting information from GP records

The process of extracting data that approved doctors are expected to follow was defined under the administrative rules drawn up for the pilot. Only information relevant to the incapacity benefit claim should have been extracted. Extracts were copied directly from the scanned GP records. These might include the handwritten or computer notes made by the GP or other practice staff, prescription records, hospital letters or investigation reports (such as x-ray or pathology), and reports from other professionals. Approved doctors were permitted to transcribe handwriting and could add their own commentary to the SB2 form drawing attention to particular aspects of the information. In the interviews, approved doctors referred to two main types of comment. The first would draw the attention of any subsequent EMO to one or more of the extracts that they should specifically refer to when they prepared their report of the medical examination (on form IB85). The second would note relevant gaps in the GP record, for example, when the claimant's IB50 reported a condition of which there was no mention in the GP record.

Two aspects of extracting information from GP records drew adverse comments from approved doctors. First, the requirement under the pilot rules to identify and extract the earliest and most recent consultation dates in relation to the claimant's relevant health condition was felt to be time consuming, particularly when the maximum of five years' records had to be examined. It could also be of very little use in cases where, for example, a decision to exempt might rely on the presence of a medical condition at the time of the claim, rather than when that condition was first diagnosed. A second criticism was that in many cases, particularly first claims, it was necessary to extract recent information. Experience had shown that in relatively few cases was there any relevant, useful information from more than two years back. Time spent trawling back five years in all cases was, therefore, unnecessary and unproductive.

The process of extracting information from GP records was a varied experience. It could be relatively easy and quick or long and laborious depending on the medical history of the claimant and the volume and quality of the GP records. (The quality of GP records is discussed in the following section.) During the course of the pilot there had been improvements in the computer software used for extracting information that had been welcome, and had reduced the time needed for the task.

Approved doctors interviewed were asked to describe how they approached the task of extracting information from GP records. Two, almost conflicting, approaches emerged. On the one hand, there was a view that only information relevant to what the claimant had recorded on their claim as their relevant health condition(s) should be extracted. The more common view, however, was that any medical information that could have a bearing on a person's functionality in relation to the IB medical assessment process should be extracted. This was based on the view that claimants are not necessarily competent to know the extent to which their various conditions (especially in combination) affect their functionality. One approved doctor explained that he wanted to prevent a situation where an EMO was faced with a claimant describing things in the examination to which there was no reference in the SB2. This would lead to unnecessary confusion and doubt.

Discussions with approved doctors about using GP records also showed that the amount and type of information extracted by some doctors had changed over the course of the pilot. At the start of the pilot, the common practice was principally to extract information that gave the '*story of the claimant's condition*' as comprehensively as possible (over the past five years). The length of the SB2 extracts varied accordingly. As the pilot progressed (and at the time of the research interviews) a variation in this approach was reported, in which greater emphasis was placed on information having a possible bearing on assessing functionality. Information giving the '*story*' was deliberately limited, for



example, to the previous 12 months (unless there was important information from earlier). However, information about functionality was rarely expressed explicitly in GP records and therefore approved doctors looked for indirect or implicit information (referred to as '*clues*' and '*hints*' by one). An example given was a reference in a claimant's records to a recent flight abroad, which might be an indication of the claimant's ability to sit for extended periods. A reference in a GP record to recent decorating might indicate the extent to which a claimant could stand or stretch. Approved doctors were therefore tending to include as much of this type of information in their extracts in order to indicate to EMOs aspects of the claimant's condition that could usefully be explored in the medical examination.

### 5.1.1 Content and standards of GP records

The point was made consistently that GP records are kept primarily to enable the GP to record their clinical findings and diagnosis and to track the treatment of their patient; they are not geared towards assessing disability and functionality. It was rare, for example, for GP records to contain information about the distances a person could walk. One approved doctor described this as a '*fundamental flaw*' in the use of GP case notes as a source of evidence for incapacity benefit assessments.

Another consistent point was that GP records varied enormously in quality (in both content and methods used for recording). Principal problems with GP records reported by approved doctors included legibility and content.

It was estimated that the percentage of handwritten notes that were illegible was between 40 and 60 per cent. Computerised notes were always legible but not necessarily more useful than handwritten notes. It had been noted that some GPs tended to write very short entries on computer compared with previous handwritten notes, which tended to be fuller. It was suggested that this may be related to GPs' age and their familiarity with using computers. Younger GPs were thought to write more than older GPs. This pattern was expected to change as GPs generally became more experienced in using computers.

Variations in the amount of information recorded by GPs in their notes also drew some criticism. In reaching this view approved doctors were drawing on perceived standards of good clinical practice. It was recognised and accepted that often GP records did not actually need to record much information, and that in busy practices there was always pressure to write notes quickly. An example was given of a stable patient whose condition required only repeat prescriptions but not face-to-face consultations. The record of such a patient was likely to be thin and of little help for benefit purposes. Nevertheless, while approved doctors described some GP records as containing a depth of information that allowed them to get a full and rounded picture of the claimant's condition and its effects, they also found that some GPs' notes clearly did not.

A separate concern was that information relevant to the claimant's health might not be contained (at least in any detail) in GP records. Sometimes, for example, a claimant might have extensive contact with health professionals other than their GP (such as community psychiatric nurses, drug rehabilitation workers, or alternative therapists) but there might be little information about these contacts in the records.

Approved doctors reported that they did not often follow up with the GP gaps in the claimant's medical history. There was a shared recognition and understanding that GPs' working lives were extremely busy and that requests for further information would generally be unwelcome. One exception to this approach was reported, however. If there was a possibility of exempting a claimant (particularly a patient with a potentially severe mental health condition) then more information might be sought in order to prevent the claimant from going through a possibly stressful assessment



process. In such cases, approved doctors used the standard form (FRP2) that allowed specific questions about the claimant to be put to the GP. This sort of approach elicited responses in around half to two-thirds of cases. It was not common practice to ask GPs for further information where their notes were illegible.

## 5.2 Using GP records at the exemption stage

As explained in Chapter 1, people with severe health conditions are exempt from the PCA. Staff in Jobcentre Plus offices are able to make exemption decisions without the need for advice from an approved doctor where it is apparent from information already held that such a condition exists, for example, where a person is receiving the highest rate care component of Disability Living Allowance. Where it appears that the claimant may have a severe condition which would exempt them, the decision maker will request the advice of an approved doctor and factual clinical information will be sought from the claimant's own doctor, usually the GP. Such cases are treated as 'potentially exempt'. An approved doctor will consider the evidence, including any report from the claimant's own doctor, and then advise the decision maker if the claimant's medical condition falls within one of the exempt categories defined in legislation.

For the duration of the pilot, approved doctors had information from the claimant's case file plus either an SB2 extract of the scanned GP records (pilot cases), or an IB113 form completed by the claimant's own doctor (non-pilot cases). In addition, for re-referral PCA cases, the claimant's Incapacity Benefit casefile contained documentation relevant to previous periods of payment, including earlier medical assessment and reports.

Approved doctors interviewed described the process of advising whether a claimant's condition fell into an exempt category as relatively straightforward. The exemption categories are defined in Regulations and information about a claimant's diagnosis and treatment was particularly useful to the approved doctor. This is clinical information; at this stage the effect of the claimant's condition on functionality was not as relevant as later stages of the PCA process.

Approved doctors reported that sufficient, relevant information was usually easily found in either the GP's records or on the IB113. However, the GP records were generally thought to contain more information than most IB113s and to give a more complete picture of the claimant's clinical condition. For some re-referral cases it was found that the picture of the claimant that emerged from GP records differed from the picture presented in the IB113 reports for previous claims. Typically in such cases the claimant's condition appeared much less severe from a reading of the GP records compared with the picture presented in earlier IB113s or other medical reports. Approved doctors reflected on this finding and speculated that had such cases not been part of the pilot it was likely that a misleading picture of the claimant would have been perpetuated in a new IB113 (and leading possibly to incorrect advice on exemption).

A possible explanation for this was suggested. It was felt that what the GP wrote on any medical form relating to benefits was influenced by their relationship with the patient. It was thought common practice for GPs to describe patients' conditions in such a way as to reflect, and not to challenge, how they presented themselves to the doctor and to ease relations with an employer. For example, while a Med4 form might give a diagnosis of 'depression' there could be nothing in the GP records that was evidence of a clinical condition. It might be more likely that the patient was unhappy in some aspects of their life, which might, in the GP's view, improve with a period of time away from work. Thus recording 'depression' on the Med4 would make dealings with an employer less problematic. The problem for benefit purposes was that such diagnoses could find themselves repeated on IB113 forms.

A positive effect of the pilot arrangements was that GP records often allowed approved doctors to form a view about the severity of a condition, and therefore whether exemption could be advised, in cases where a simple diagnosis would not allow this. An example cited here was where a diagnosis of 'depression' appeared on an IB1 13 without further elaboration from the GP. From this information alone an approved doctor would not be able to assess whether the claimant was suffering from a 'severe mental illness'. In such a case, the claimant would be asked to complete an IB50 in the usual way. However, a GP record might provide additional information that would allow a decision to exempt to be made. A similar example, but leading to a different outcome, was where schizophrenia is given on an IB1 13 as the primary diagnosis. Under the usual arrangements, such a diagnosis would be likely to lead to advice to the decision maker to exempt the claimant. This was described by an approved doctor as giving the claimant *'the benefit of the doubt'*. However, GP records showing that a patient's schizophrenia was well controlled and that the patient was living in a stable environment, for example, might suggest that 'severe mental illness' was not present and that exemption was not justified.

Based on their experiences of the pilot at the time of interview, approved doctors reported an increased level of confidence in their advice to decision makers about whether to exempt, or not exempt, which derived from the fuller information available from the claimant's GP record. However, this increased confidence should not be overstated; approved doctors were already generally confident in the correctness of advice based on the information in IB1 13 forms.

It was hard for approved doctors to assess whether they were advising more exemptions under the pilot. This was partly because so few cases appeared eligible for exemption under the usual arrangements, making it difficult to identify a change. It was also partly because the effect on advice of using GP records was not perceived as only in one direction. As described above, the additional information in GP records could lead equally to advice to exempt or advice not to exempt depending on the nature of the information.

The process of providing advice about exemption was thought to take slightly longer under the pilot arrangements, because it was necessary to examine the GP records to identify the appropriate diagnosis. In contrast, a diagnosis was usually quick and easy to find on an IB1 13.

In summary, approved doctors expressed a preference for using the SB2 extract of the GP records to provide advice about exemption. IB1 13 forms were satisfactory for the purpose in most cases but they varied in quality. GP records were more consistently useful in comparison. However, the impact on the substance of the advice provided was thought to be marginal.

### 5.3 Using the SB2 extract of the GP records at the PCA scrutiny stage

At the 'scrutiny stage' of the incapacity benefit PCA process, approved doctors are required to advise a decision maker as to whether a claim can be accepted without a medical examination of the claimant or whether an examination is necessary.

To provide this advice, approved doctors examine all the evidence before them. For pilot cases, this included a completed SB2 form with extracts from the GP record. For other cases, there may have been an IB1 13 report or a Med 4 form from the claimant's GP.

One of the planned outcomes of the pilot was a reduction in the number of cases sent for examination after scrutiny. It was expected that the information available from GP records would enable approved doctors to advise on more claims without an examination than under the usual (non-pilot)

arrangements. The experience reported by approved doctors was the opposite however. In their view, there had been an increase in the proportion of cases scrutinised and then called for examination. The additional evidence available in pilot cases was thought to have provided information which raised doubts in the minds of the approved doctors about whether the claimant's score reached the appropriate threshold of 10 or 15 points. This was particularly the case in relation to re-referral cases. Several contributory reasons were suggested:

- Because of the **amount** of information. There was more information in the records that was relevant or up to date. On re-referral cases in particular, advice under the usual arrangements was sometimes made, relying on information from older claims. If there was no evidence that anything had changed, then an assumption was often made (in the claimant's favour) that nothing had actually changed in practice and the claim was passed. The pilot had shown that some of these assumptions were probably unjustified
- Because of the **scope and extent** of the information. There was a feeling that some GPs presented only a partial picture of their patient on an IB113 which would count in their favour for benefit purposes. In contrast, GP records might show (for example in hospital reports) degrees of improvement not reported on the IB113.
- Because of the **accuracy** of the information. The diagnoses recorded on the IB113s or Med3s and Med4s were sometimes not borne out by the GP records.

In contrast, approved doctors also reported that there had been cases where the information from the GP records had allowed them either to advise exemption or to advise on cases at the scrutiny stage, that under the usual arrangements where IB113 information was available would be sent for examination.

In comparing the relative merits of SB2s and IB113s, approved doctors reported that using information from the GP records allowed them to provide '*stronger*', better justified advice to the decision maker. There was agreement however, that when IB113s were completed well by GPs, their advice was equally good. Medical information was not intrinsically '*better*' in SB2s compared with IB113s, but it was different. Fuller clinical information was generated in the pilot, but a good IB113 would contain more information about the effects of the patient's condition. Both systems could work well, therefore, but both were reliant on good information from the GP whether directly from the records in the case of the pilot or from an IB113 in the cases of the usual arrangements. Whether an IB113 was completed by the GP or a member of the practice staff was not a major issue with approved doctors. It was recognised that it was usual practice in some surgeries for practice staff to fill in parts or all of the IB113 form<sup>11</sup>, and experience had demonstrated that some forms completed by, for example, practice nurses, were as useful or better, than some completed by GPs.

## 5.4 Overall views of approved doctors

Approved doctors in Leeds expressed an overall preference for an advisory system based on information from GP records rather than the existing system that relied on GPs completing an IB113 form.

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<sup>11</sup> Notwithstanding which individual within a GP practice writes information on the IB113 the GP has overall responsibility in all cases for providing medical information to the approved doctor.

The advantages were summarised as follows:

- GP records could potentially be collected on all cases; at present only a proportion of IB113s were returned by GPs.
- Although GP records varied in quality, many compared favourably with the quality of IB113s.
- GP records could contain fuller, more accurate, more objective and more up-to-date clinical information than many IB113s.

It was felt that GP records were particularly useful for re-referral cases where there was often little up-to-date information supplied on an IB113. They were also useful for claims from people with mental health conditions because the diagnosis on an IB113 was often insufficient to allow them to advise about exemption.

Criticisms of the pilot arrangements included the following:

- Administrative rules set up for the pilot were too rigid. Information relating to first and most recent consultations, and information spanning five years was not always necessary.
- GP records did not contain much direct information about functionality (compared with 'good' IB113s).

In Chapter 7 we return to the experiences of approved doctors and consider how their reflections and observations can inform thinking about the use of medical information in the future.



## 6 Using the SB2 form in the medical examination and in decision making

This chapter presents the experiences and views of approved doctors acting as examining medical officers (EMOs) and of benefit decision makers in Jobcentre Plus about the pilot arrangements and the usual methods for processing incapacity benefit claims. For pilot cases, the EMO would have had access to the SB2 (extract of relevant details from the claimant's GP records) and this form would also have been available to the benefit decision maker. At no time did the EMO or decision maker have access to the full scanned GP records.

For the purposes of this research, all six EMOs, who were carrying out regular examinations of incapacity benefit claimants under the pilot arrangements, were interviewed. Each had had specialist training on using the information contained within the SB2 form as part of the medical examination. We also involved all ten Jobcentre Plus incapacity benefit decision makers in Sheffield and Rotherham in the research. Six were interviewed individually, and four took part in a group discussion.

Section 6.1 describes the role of EMOs in the administration of incapacity benefit and how they use medical information. Section 6.2 presents findings of the impact of the pilot arrangements on the work of EMOs and Section 6.3 compares the relative advantages and disadvantages of using SB2 and IB113 forms under the pilot and usual arrangements. Section 6.4 summarises EMOs' views of the pilot. In Section 6.5 the role of the Jobcentre Plus decision makers is explored, before presenting findings on the impact on their work of the pilot arrangements in Section 6.6. Section 6.7 compares how the SB2 and IB113 forms contribute to the decision-making process from the perspective of decision makers, and the final part of the chapter summarises their overall views of the pilot.

### 6.1 The role of Examining Medical Officers

The role of examining medical officers is to examine incapacity benefit claimants and to produce a medical report for the use of Jobcentre Plus decision makers. EMOs see only a subset of incapacity benefit claimants largely comprising those where there is insufficient evidence or where the available evidence casts doubt on their functional incapacity. Following an examination of the claimant, EMOs provide advice to the decision maker in the form of a detailed written report.

A medical examination may comprise a physical examination of the claimant and/or, where there is a mental health problem, a mental health assessment. All examinations are conducted face to face and usually take place in a designated Medical Examination Centre.

In preparing for a medical examination the EMO has access to the documentation held by DWP relating to the claimant. There may be considerable information about claimants with a long history of claiming Incapacity Benefit, or relatively less for new claimants. For pilot cases, the information included an SB2 form. For non-pilot cases there may or may not be an IB113 medical report or a Med 4 statement from the certifying medical practitioner, usually the claimant's GP. EMOs explained that they used the information available to identify particular aspects of the claimant's medical history or functionality that they would need to explore in the medical examination.

EMOs all said that they routinely explained in general terms at the start of the face-to-face examination with the claimant that medical information had been collected from GPs, hospitals and others. Some claimants were reported to be particularly concerned to know that a full history of their condition was contained in their case file and wanted reassurance that the EMO was knowledgeable about their condition. However, EMOs were clear that they did not refer to specific pieces of medical information or their source during the examination. No EMO had mentioned to a claimant that they had extracts from GP records. It was explained that there was a risk of damaging the relationship between GP and patient if the latter inferred at a later date that information from their GP had led to a disallowance. EMOs were acutely aware that relationships between GPs and patients were sometimes fragile or vulnerable.

The role of the EMO after the examination is to complete a medical report form, IB85. This form contains the same set of descriptors as the IB50 completed by the claimant. EMOs must advise the decision maker with a choice of descriptor in each of the functional categories and must justify that choice with medical evidence and reasoning. Under the pilot arrangements EMOs were required to make a reference at the appropriate place on the IB85 to any relevant information in the SB2 form.

## 6.2 The impact of the pilot arrangements for Examining Medical Officers

There was a general consensus among EMOs that the pilot arrangements had little impact on the process of examining claimants and on the choice of descriptors they made. There was less consensus on the impact of the pilot on the content and depth of their medical reports.

There was some surprise at the lack of impact on medical examinations. Some EMOs had looked forward to having, at hand, detailed clinical information in the SB2 forms. When EMOs were asked to reflect on the perceived lack of impact, several possible explanations emerged. It was noted that the job of the EMO was to make judgments about functionality, but information about functionality was rarely contained in SB2 extracts. In order to make choices of descriptors they relied far more on what they found at examination, where they were able to make direct observations about functionality, or ask questions about functionality of claimants with mental health conditions. One EMO commented that the amount of time spent with a claimant was substantial (around 30 minutes was common), particularly in comparison with the average GP consultation time. A considerable amount of relevant information could be collected in this time and was usually the main influence on the choice of descriptors.

No EMO said that extracts from GP records hindered them in the job of examining, and most expressed some level of interest or approval. Some liked the fuller medical histories that were contained in SB2s, but it was not common that the additional information available had much effect

on individual cases. For one EMO, this was both disappointing and reassuring. It was thought beforehand that information like hospital reports, or results from x-ray or pathology tests, would have an important positive effect on the types of decisions EMOs made, but this was not the experience. This was disappointing. However, it was also reassuring to know that in the absence of such information in the past decisions about descriptors were as good.

Although EMOs felt there was no apparent effect on their choice of descriptors, it was reported by some that decisions about re-referral dates had been influenced by information from GP records. For example, the record may contain firm dates of forthcoming operations or other relevant procedures. One EMO commented that in a few cases it was possible to set a longer re-referral date because of the fuller information in the SB2. (In the absence of such clinical information it would be usual practice to set a shorter re-referral date.)

One anticipated impact of the pilot was that EMOs would see fewer claimants who, in their assessment, were eligible for exemption because these would have been identified earlier in the process by an approved doctor scrutinising the paper evidence, including the extract from the GP record. However, it was hard for EMOs to make an assessment about whether they were making fewer decisions to exempt at the medical examination stage. This was partly because EMOs were still seeing many non-pilot cases as well as pilot cases throughout 2002 and distinguishing between the two types at the time of the research interview was not easy. One EMO mentioned that the most recent cases, where exemption had been advised following an examination, were non-pilot cases.

EMOs all commented that the pilot arrangements had affected the way in which they completed IB85 medical reports. They all reported spending more time on the reports because of the requirement to make reference to the SB2 in the justifications for descriptors. Some said that they felt their advice was better justified and as a result had an increased level of confidence in their correctness. Others did not feel able to offer an assessment here, but none said there had been an adverse effect on their reports.

## 6.3 Examining Medical Officers' experiences of using SB2 and IB113 forms

EMOs were asked to reflect on the ease of use of SB2 forms in comparison with IB113 forms in use on non-pilot cases. Comments covered a number of different aspects.

### 6.3.1 Information about functionality

It was generally acknowledged that GP records were not a good source of information about functionality. One EMO, however, did not share that view, suggesting that clinical information could yield strong indications about a person's likely functionality. (An example was given where an SB2 might refer to a recent leg injury or operation from which some idea about the claimant's ability to walk could be inferred.) It was felt that the IB113 had the greater potential for generating information about functionality because the wording of the form gave the opportunity to GPs to provide such information. In practice, however, many IB113 forms contained little or no such information.

### 6.3.2 Objectivity of medical information

It was felt by some EMOs that the information extracted from GP records was likely to be factual and objective. In contrast there was a feeling that some IB113 forms were completed by GPs in a more subjective manner, presenting information in such a way as to promote their patient's claim for benefit. (Comparing this view with the evidence from GPs presented in Chapter 2, it seems that this feeling would be justified in some cases.)



SB2 forms were also felt to contribute to objectivity in a different way. It was observed by some EMOs that the picture of a claimant's health that emerged from the GP's own notes sometimes differed from that emerging from hospital and other records. One possible explanation for this was felt to be the possibility that some people present themselves in different ways depending on their perception of the purpose of the interaction. The way patients talk about themselves to a GP, from whom they might want a medical certificate, may thus be different from the way they talk to hospital staff, from whom they are seeking treatment. The information in SB2 forms from external sources was therefore thought to act as a useful check on the validity of the information recorded in GP case notes.

### 6.3.3 Appropriate period for extracting medical information

This was an issue relating to the pilot only. As explained in Chapter 1, five years was chosen as the time period for which approved doctors would extract information from GP records in the pilot. There is no comparable time limit imposed on GPs completing IB113s, who are free to present information going back as far as they see fit.

There were mixed views about whether five years worth of medical information was useful to EMOs. The dominant view was that in assessing functionality only more recent information was necessary, perhaps over the past two years (possibly three years). It was rare that information going back five years was needed. A different view was that five years' information was often useful in gaining a good understanding about the claimant's current health status, and that it would be preferable to maintain this period if the pilot arrangements were adopted in the future.

### 6.3.4 Gaps in information

There was general agreement that neither the pilot nor the usual arrangements were designed to generate information directly from other health professionals, such as mental health teams, rehabilitation workers or carers. However, there were differing views about whether this was an important omission. One view was that such information would be valuable and likely to be more relevant to functionality than factual clinical data. This would be particularly useful when the treatment of a patient did not require them to have direct contact with their GP. A counter view was that information from psychiatric or other support workers was likely to be couched in terms favourable to the claimant, and hence, too subjective to be useful. One EMO was able to draw on previous experience of working as a tribunal member to support this with a view that information provided at tribunal hearings by support workers was often more hindrance than assistance.

### 6.3.5 Understanding the claimant's medical history

One, minor, criticism of the SB2 reporting arrangements was that it was sometimes necessary to piece together the claimant's medical history from the chronological extracts in the SB2. This was more of a chore when the claimant had multiple health conditions. In comparison, the IB113 was much easier to read and understand because the GP usually gave a coherent summary of the claimant's health.

### 6.3.6 Legibility

Legibility of GPs' handwriting was an issue for both SB2s and IB113s. It was welcome that many GP records were computerised, and copies of hospital letters were always legible. There was some criticism that hard-to-read extracts were not always transcribed by the approved doctors in Leeds.

## 6.4 Examining Medical Officers' overall views of the pilot

EMOs were asked if they had a preference for working with the pilot arrangements or the usual arrangements. No clear view emerged. There were supporters of each whilst some preferred to reserve their judgment.

Preferences for the pilot arrangements were based on the following reasons:

- A system where *some* information was almost guaranteed was preferable to the current arrangements when many cases had no IB113s, and many of those returned were of very limited, or no, use.
- The information in SB2s gave a more complete clinical picture of the claimant.
- SB2s were considered more objective than IB113s.

Disadvantages with the pilot arrangements included:

- the additional time required to deal with cases; estimated at between five and ten minutes per case (in order to read and assimilate the information and to write more detailed IB85 reports);
- lack of direct information about functionality.

The main advantage of the usual arrangements was that IB113 forms contained questions specifically designed to elicit relevant, useful information about functionality.

The final observation from EMOs was that what they required was high quality information. Whether this came via an IB113 or in extracts from GP records was less of an issue. IB113s could be excellent, and equally when a GP's original records were poor, an SB2 could be of little use. Some EMOs thought that variety in GP responses to IB113s would always exist, and hence an alternative system was preferable. Others had suggestions for building on and improving the current arrangements. We return to these in Chapter 7.

## 6.5 The role of Jobcentre Plus decision makers

Jobcentre Plus decision makers have a specialist role within the administration of incapacity benefit. Most of their work is concerned with deciding cases in which a Personal Capability Assessment (PCA) has been required but the advice from the EMO indicates that the claimant has not met the PCA criteria at the medical examination stage. There are two main types of case, therefore, that come before them for consideration. First, cases in which the claimant's IB50 has been scored at less than the threshold level and the EMO has similarly scored them at less than the threshold. Decision makers described these cases as straightforward and easy to decide as disallowances because there was no conflict of evidence. The second type of case was where the IB50 score differed from the EMO's assessment, i.e. there was a conflict between the choice of descriptors by the claimant and EMO.

Information provided by certifying medical practitioners (on an IB113 form, a Med 4 statement or via an SB2 extract of GP notes) is primarily for the use of the approved doctor (a DWP medical officer). Such evidence is used by the approved doctor to provide advice to the benefit decision maker. However, once used by the approved doctor, this evidence also becomes part of the claimant's incapacity benefit case file and is available to, and may be used by, the benefit decision maker.

Decision makers reported that in cases where the EMO scored the claimant above the threshold but the claimant's IB50 was scored below, it was usual that the assessment of the EMO would prevail and an award of incapacity benefit would be made. In contrast, cases where the IB50 had been scored

above the threshold but the EMO report gave a score lower, caused decision makers the most difficulty. The task for decision makers here was essentially to decide between one or more competing PCA descriptors.

Decision makers described the usual process of dealing with this type of case, for which they had access to all the material contained in the claimant's case file, including claim forms and medical reports from previous claims. Decision makers first looked at the choice of descriptor and any supporting information from the claimant on the IB50 and from the EMO on the IB85 medical report form. It was clear, from the decision makers, that these two documents were the principal sources used. If there was information from the GP available (in an SB2 for pilot cases, and an IB113 for other cases) then this would also be examined to identify anything that would support either the claimant's or the EMO's choice of descriptors.

Decision makers described their task as being reliant on good quality information. One of the aims of the pilot arrangements was to improve quality of information in the expectation that the quality of decisions on incapacity benefit claims would improve as a result. The next section presents findings on the impact on the pilot arrangements on these two aspects of quality.

## 6.6 The impact of the pilot arrangements for decision makers

There was a general consensus that the pilot arrangements had had little impact either on the quality of IB85 medical reports produced by EMOs or on the substance or quality of decision makers' own decisions. Both these experiences were reported by decision makers with a degree of surprise and disappointment. There had been an expectation of a much greater and more beneficial effect from having access to information from GP records.

Decision makers reported that changes in the quality of IB85s were not easy to identify because there was already a variation in the type and amount of information provided by different EMOs. During the period of the pilot these variations persisted.

There was some recognition that in IB85s for pilot cases, the choice of descriptors was almost always accompanied by some form of justification that referred to the SB2. In itself this was useful in demonstrating to decision makers that EMOs had actually consulted the SB2. However, what was written in the IB85 as justification was not always useful. One decision maker reported that references such as 'no relevant information on SB2' or 'I have taken into account the contents of the SB2' did not help them understand how the SB2 information (or lack of information) influenced their decision.

All the decision makers interviewed said that they had not noticed any effect on their decisions from the pilot arrangements. However, some decision makers who had seen relatively few cases, found it hard to offer an informed assessment here. In contrast, some were definite in the view that the pilot had had no effect, saying that they thought their decisions would have been exactly the same under the usual arrangements. It was also difficult for decision makers to judge whether they had more confidence in pilot case decisions. Any information that supported their decisions was useful. This came from SB2s in some cases and from IB113s and other sources in other cases. There was no feeling that the pilot arrangements had particularly increased their confidence in decisions.

## 6.7 Decision makers' experiences of using SB2 and IB113 forms

Decision makers were asked to reflect on their experience of using SB2 forms in comparison with using IB113s on non-pilot cases. Comments covered a number of different aspects.

### 6.7.1 Relevance of information

All the decision makers interviewed had views about the type of information extracted from GP records and presented in SB2 reports. There was a common understanding that the information was intended primarily for the use of approved doctors, including EMOs, and not for them. They found it difficult to interpret and understand some of the clinical information, much of which contained technical terms and expressions. Diagrams drawn by GPs in their notes were particularly difficult to understand. They felt unable to use much of the information in the SB2, therefore, and reluctant to make guesses or assumptions in case they made mistakes. In contrast, information that related to the claimant's functionality was welcome and easier to understand and use. There was a feeling that IB113s were generally better at providing such information when they were completed well by GPs. They were also less likely to contain technical jargon. However, there was the recognition that many GPs failed to return IB113s and that of those that were filled in, probably many were of little or no use because of the paucity of information provided.<sup>12</sup>

It was recognised that IB113s were filled in by non-GP staff in some practices. There was no strong feeling about the acceptability of this and it was noted that forms completed by nursing staff were often better than many filled in by GPs.

Decision makers described a range of resources they could use when they were unsure about some aspect of a case. These included the knowledge and experience of their colleagues, guidance and reference materials (such as Black's Medical Dictionary), and the knowledge of approved doctors (in the Leeds Medical Services Centre or in local Medical Examination Centres). Decision makers tended not to consult approved doctors very often, but they had proved useful in explaining medical conditions and terms that occurred only rarely. GPs and claimants were not consulted for further information.

### 6.7.2 Legibility

Legibility of handwriting was a source of serious concern and frustration for decision makers. It was impossible to make use of illegible information in SB2s or IB113s. There was again some surprise and disappointment that illegible extracts from GP records were not always transcribed by approved doctors. The point was made that if an extract had been selected then presumably a doctor had been able to read it at some stage. That few transcriptions appeared in SB2s reinforced the perception that they were intended for the use of approved doctors, including EMOs, primarily.

There was also concern that some handwritten IB85s were difficult to read. However, in such cases, the decision maker could send the case back to the relevant EMO or consult them directly. This was an irritation to decision makers and EMOs and slowed down the progress of the case.<sup>13</sup>

<sup>12</sup> One of the reasons why cases are referred for examination is a lack of medical information, which is often the result of poorly-completed IB113s. It is likely, therefore, that of the IB113s seen by decision makers, a relatively high proportion will contain little useful information. Another reason for little medical evidence being available for many cases is the IB113s are only sought in about a third of cases.

<sup>13</sup> As explained in Chapter 1, a concurrent pilot was exploring EMOs' use of a computer based system for completing IB85 reports. Towards the end of the fieldwork period, this pilot was being extended to other areas including Sheffield and Rotherham.

### 6.7.3 Confidence and trust

Several decision makers reflected on an aspect of their work that had been affected by the pilot arrangements. They commented that, in all cases, pilot and non-pilot, they needed confidence and trust in the material they had to work with. In using SB2s it appeared to them that extracts were often taken from longer reports or letters. Sometimes extracts ended in mid-sentence. Although it was recognised that an approved doctor might intentionally extract only part of a sentence, it was hard for decision makers to be certain. Doubts could therefore arise as to whether something had been missed and cause a reduction in confidence about decision making.

A different concern was raised in relation to IB85 reports. Here the issue was the use by some EMOs of the same phrases and forms of words in reports for different claimants. What decision makers preferred was an explanation in the IB85 that linked information about the claimant's condition in either the SB2 or IB113, and findings in the medical examination to the EMO's choice of descriptor. The effect of using the same phrases was that this link was not convincingly made and this reduced decision makers' confidence in their decisions.

## 6.8 Decision makers' overall views of the pilot

Decision makers were asked if they had a preference for working with the pilot arrangements or the usual arrangements. No strong views were expressed and no consensus emerged.

Some decision makers thought the principle of the IB113-based system was superior to the pilot arrangements even though there were well known deficiencies in how the system worked in practice. When IB113s were completed well, they presented an easy to follow summary of the claimant's medical history and information about functionality. SB2s rarely matched this level of usefulness. There was a slight preference among these respondents for thinking about ways of improving and building upon existing arrangements. Other decision makers acknowledged that it was preferable to have *some* information from GPs on all cases rather than very variable information on only a proportion.

Neither the current arrangements nor the pilot arrangements were seen as ideal templates for the future. However, decision makers were clear that medical information was essential to their task. The experience of working under both systems prompted decision makers to make a number of suggestions about how medical information could be generated in the future. Chapter 7 presents these, alongside the ideas from the other actors in the incapacity benefit decision making process.

# 7 Developing policy for the collection of medical evidence

In the first part of this chapter we bring together the views and experiences of all the actors in the administration of incapacity benefit on a number of policy issues relating to the use of medical evidence. Other issues have been prompted by the analysis of research data by the research team. In thinking about the future of Incapacity Benefit these issues will need careful consideration by policy makers in any reforms to the administrative arrangements for incapacity benefit.

Section 7.2 presents ideas and suggestions about how collection of medical evidence might be improved in the future. These fall into ideas for building on the current system based on the IB113 forms, for building on the pilot arrangements, and other, related ideas for generating useful and relevant information.

The final part of the chapter presents conclusions from the study.

## 7.1 Issues for policy

### 7.1.1 Acceptability of using GP records

The main objection of principle among GPs and claimants not participating in the pilot, was that releasing GP records to people, including medical practitioners, working on behalf of DWP would breach the confidentiality of those records. It is possible that some GPs' objections might be overcome if they were satisfied that their patients had given informed consent to the release of their records. (We return to the issue of consent below.) However, it could be more difficult to persuade reluctant claimants, whose records might contain sensitive information about themselves or their families, about the desirability of allowing GP records to be used by DWP approved doctors and for a relevant extract to also be available to the benefit decision maker. Some expressed distrust about how information would be used, and suspected that there might be other, negative outcomes for them or other claimants. Some GPs held to their belief that the pilot arrangements were wrong in principle and remained opposed to them.

Other objections to the pilot arrangements related to the possible adverse effects of GP records leaving the practice premises. These included the unavailability of records when required, and the possibility of records getting lost, damaged, or being returned in a disorganised state. From the evidence of the participating GP practices, however, no such problems arose in the course of the pilot. Case files were collected and returned satisfactorily and within the three day target period. In addition, some practices had introduced their own back-up procedures (such as keeping copies of the patient's most recent records) to guard against any potential problems. The implication, therefore, is that it is possible to design systems for collection and return that should not interfere with the clinical work of GPs and which might reassure some claimants if they were explained to them.

### 7.1.2 Gaining informed consent

From the interviews with incapacity benefit claimants it was clear that overall there was little understanding of what and how medical information is used in determining their claims, variable recognition of explanations about the pilot arrangements contained in DWP letters or leaflets, and variable understanding and sometimes little interest in what was contained in GP records. Some GPs' suggestions that some people might not have sufficient knowledge to give informed consent would therefore seem to be well-founded.

In discussing the consent procedures for the pilot, GPs in this study mentioned that informed consent is an integral element of the design of therapeutic and drug trials that was very familiar to them and also that they were used to releasing records or providing photocopies to third parties, including solicitors and insurance companies, through the provision of the written consent of the patient. For the pilot, obtaining written consent involved the claimant being sent an information sheet and then ticking a box as part of the main declaration on one of the relevant forms if they did not want to take part.<sup>14</sup> Some GPs questioned whether, under this method of obtaining consent, people would be fully aware of what they were agreeing to. It is possible that, given the lack of understanding shown by both those who participated and those who did not participate in the trial, more robust procedures for informing clients to allow them to decide whether or not they wish to participate would need to be considered if the pilot arrangements were to be adopted more widely. Apart from its intrinsic desirability, some GPs will need to feel more confident that their patients are sufficiently aware of what they are agreeing to and might prefer a different method of gaining written consent from patients.

### 7.1.3 Effects on GP practice office staff

The pilot created a new set of administrative tasks for GP practice staff. Some managers felt that the work created by the new tasks was no more time-consuming than working under the usual arrangements. Others reported an overall increase in their workload. The assessment by practice managers and other administrative staff about how much extra work was created varied. Practices that chose the photocopying option seemed to have experienced the most additional work; those that supplied actual records seemed to experience the least. Practices that were fully or partly computerised had to print out records in addition to handling a case file and their workload varied.

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<sup>14</sup> These were forms that claimants were required to complete in full and sign as part of their declaration underpinning their claim to benefit or as part of the PCA process. The information leaflet for claimants attached to claim forms and IB50s explained that further enquiries could be made to a Jobcentre Plus office.



An assessment of the additional work imposed on GP practices will be relevant to decisions about appropriate remuneration under any future arrangements. The additional £10 honorarium per case record sent was not a major reason for GP practices' decisions to participate, although it was clearly seen as welcome. However, it is possible that if the photocopying option was available in the future then GP practices would require more than the £20 additional honorarium paid as part of the pilot, and for additional reimbursement for potentially large amounts of printout and scanned material.

As mentioned above, one influence on the impact on GP practice staff was the extent to which the practice used information technology. Among the practices visited in the course of this research there was a wide range in the use of computers. Some made little use and relied on a paper-based system of records; others were what they called 'fully computerised' and 'paperless'. There were some examples of innovative and creative thinking about how the use of computers could be extended. Of particular interest for this research was the development of software to enable extracts from GP records to be input directly onto medical report templates and other forms, and ideas about the use of email for responding to requests for medical information. Thinking about future arrangements will need to take account of the diversity in the use of information technology, and the possibilities and implications it presents.

#### **7.1.4 The role of practice managers**

In collecting research data during the visits to GP practices, it became clear that practice managers have played a number of key roles during the course of the pilot. They have acted as the channel through which the invitation to participate reached GPs, they contributed influentially to decisions about participation, they made the practical arrangements within practice offices and often carried out most or all of the tasks associated with participation, and importantly they have fed back to GPs their experiences of the pilot. The last of these has been important in forming some GPs' views of the pilot, though it was clear that, at the time of the research interview, other GPs were not aware of the administrative impact of the pilot.

In thinking about the implementation of any future arrangements, therefore, the views and experiences of practice managers could be particularly useful.

#### **7.1.5 Assessing functionality**

A common theme emerging from the interviews with staff within Medical Services and Jobcentre Plus was the general difficulty of assessing the functionality of claimants. A strong view emerged that information contained in GP records (and subsequently extracted on to SB2 forms) was not generally well suited to assessing the extent of a person's capability for carrying out the functions of everyday living. This is not surprising. GP records are kept for the primary purpose of recording clinical findings and to support the management of a patient's condition. From the accounts of the approved doctors in Leeds and from GPs themselves, it is clear that GP records vary widely in the amount and quality of functional information recorded.

Overall, GP records were considered generally good for arriving at a diagnosis of the claimant's health condition or conditions. They were, therefore, useful for approved doctors providing advice about exemption, but of less use for EMOs and decision makers making assessments and judgments about functionality.

In contrast, a 'good' IB113 could contain information useful to all the people in the decision making chain, because it would contain diagnostic data *and* information relating to the tasks of everyday living. The problem for approved doctors, EMOs, and decision makers, was, as we have mentioned at various points in this report, that only in a minority of cases was a 'good' IB113 available.



Some interesting observations emerged in the research interviews about assessing functionality for claimants with a diagnosis of mental illness or who had completed the mental health questions in the IB50 form. It was a common view that the effects of any particular mental health condition could vary considerably between individual people. It was therefore difficult to arrive at a view about functionality from GP records alone. The pilot arrangements were generally felt to be more useful for claimants with only physical health conditions.

### 7.1.6 Sources of relevant information

It was generally recognised that some information that would assist people at the different stages of the decision-making process was not routinely or always to be found within GP records. This concern was expressed strongly by some claimants interviewed. Examples cited earlier in this report included information from mental health professionals, rehabilitation workers or carers. There was no consensus about the practical value of such information however. Some people in the decision-making chain advocated that greater effort should be made to collect information from other professionals because it was useful in assessing functionality. Others were wary about a possible lack of objectivity among people whose professional job was to act as supporters and advocates of their clients. While factual, objective information about functionality could be useful, information presented in the form of a supportive statement or argument was of much less use.

Possible lack of objectivity in GPs' IB113 reports has already been mentioned as a concern of some respondents and used as an argument for using GP records in their place.

### 7.1.7 Appropriate period for extracting medical information

An issue for policy is the question of what is the most appropriate period of time for taking extracts from GP records. For the purposes of the pilot, a period of up to the previous five years had been selected.

There was a general feeling that it was not possible to prescribe a 'best' period. It was recognised that for some people with chronic conditions, it was desirable to have information going back several years. In some cases, possibly most, five years would be adequate. In other cases, information going back further would be appropriate. However, there was a view that, particularly for new claimants, the onset of the condition that had led to a claim for incapacity benefit was likely to have taken place only in the 12 months prior to the claim. Earlier information was unlikely to be relevant in most cases.

In discussions about appropriate time periods, the researchers noted that some GPs and claimants talked exclusively about information needed to understand the development of the relevant health condition (the medical history or 'story' as we refer to in Chapter 4). Staff involved in the decision-making process spoke more about their need for information about functionality. In their view, little could be learned in most cases about a claimant's functionality, at the point of the incapacity benefit claim from clinical data going back five years. For new claimants in particular, therefore, they would be happy to have information for a shorter period. Between 12 and 24 months was suggested as satisfactory.

### 7.1.8 The stock of incapacity benefit claims

The stock of incapacity benefit claimants have been in receipt of the benefit for varying lengths of time, some for many years. One effect of the pilot, noted by approved doctors and reported in Chapter 4, was that having access to GP records had given them more information than in the past about the claimant's health condition. For long-term claimants the outcome had sometimes been a call for medical examination, whereas in the past, they might have been passed at the scrutiny stage.

For other claims, re-referral dates were set for longer periods than might have been the case under the usual arrangements. Typically, in the past, long-term claims would have been assessed on somewhat out-of-date information in the claimant's case file, perhaps supported by an IB1 13 that recorded only 'no change' in their condition.

The implication drawn from this experience was that there might be, in the wider incapacity benefit claiming population, claimants who, if assessed fully in a face-to-face medical examination, would no longer meet the Personal Capability Assessment thresholds. If the pilot arrangements were extended nationwide this might lead to an increase (though possibly temporary) in disallowances at the re-referral stage and a rise in appeal levels.

### 7.1.9 Appeals

One of the hoped for outcomes of the pilot arrangements was a decrease in the number of appeals lodged by unsuccessful claimants, and a reduction in the proportion of appeals that eventually succeed at a tribunal. The rationale for this was that the pilot arrangements would produce better, more accurate decisions because they would be based on information extracted directly from GP records. If this was understood by unsuccessful claimants then there would be greater confidence in, and acceptance of, disallowances. Furthermore, if appeals were still made then the decision was more likely to be upheld at a tribunal.

This research project was not designed to evaluate what impact the pilot was having on appeals. (Further work in this area will be carried out in 2003 and reported separately.) However, approved doctors and Jobcentre Plus staff were asked about their views about the impact on appeals. From those who felt able to offer a perspective there was an emerging view that the pilot arrangements are unlikely to have much of an effect at the appeal level. There were two main reasons for this.

First, the motivation for claimants to appeal, particularly in the view of Jobcentre Plus decision makers and processing staff who may have contact with them, has little connection with the soundness of the original decision. From their experience, claimants are rarely interested in understanding decisions but in getting them changed. Furthermore, decision makers said that if the occasion arose under the pilot arrangements they would almost certainly not mention to a claimant that they had seen an extract from their GP records. This echoes the comments of EMOs, who were clear that they did not, and would not, tell claimants the exact nature of the medical information before them (in order not to risk GP-patient relations). Hence if claimants are not told (or reminded if they knew at some stage) about how GP records have fed into the decision, then such knowledge cannot persuade them that the decision was correct.

Secondly, there was a degree of concern expressed about the decision-making processes of tribunals. In the perception of some research participants, tribunals are sometimes unduly influenced by what appellants tell them or new information provided by third parties and pay less attention to the information used in making the original decision. There was little confidence, therefore, that clinical information contained in the SB2 extracts from GP records would change this.

## 7.2 Lessons for running pilots

As mentioned earlier in the report, some of the research participants commented positively on being invited to participate in a pilot exercise and saw this as a sensible and appropriate way of informing and developing public policy. Some also made specific comments about how the pilot was being run that could be useful in thinking about the use of pilots in the future.

Robust projections about numbers and types of likely pilot participants are important to avoid major changes to design and timetable. Staff need to be kept fully informed about the pilot not only in advance of its commencement but also when changes are made to the pilot design later. In this pilot, not all staff were aware of the extended timetable or the inclusion of re-referral claimants (these changes are described fully in Appendix A). Staff who are involved in putting the pilot arrangements into practice said they would have welcomed more support and guidance. Smooth running of pilots depends partly on the commitment and effort of a range of staff and can be jeopardised by drops in morale or feelings of isolation. Staff working in Jobcentre Plus offices need to be informed about pilot arrangements also. It is likely that they will have to deal with some enquiries during the period of a pilot from participants. Many research participants were interested to hear about the progress of the pilot. Early thought needs to be given as to how feedback to all the participant groups will be handled. Telling people what and when they will receive this could contribute to levels of participation and help to maintain commitment during the pilot.

## 7.3 Views on improving the collection of medical information

All the research respondents were invited to reflect on the best way of collecting medical information and whether they could think of improvements for the future. Respondents naturally gave their views from a number of different perspectives (for example, as pilot participants or non-participants) and from different knowledge and experience bases. The ideas and suggestions generated are summarised below and are intended as a stimulus to policy thinking. It was beyond the remit of the respondents and beyond the scope of the research project to evaluate or cost them.

The suggestions made fell into three broad groups:

- Ideas based on continuing with the current arrangements based on IB1 13 forms.
- Ideas based on the pilot arrangements.
- Other ideas, not specifically related to the usual or pilot arrangements.

These are discussed below.

### 7.3.1 Ideas based on continuing with the current arrangements based on IB1 13s

Some people taking part in the pilot preferred the current arrangements of collecting medical information to the pilot arrangements. For some there were fundamental objections of principle to the pilot. For others their view was based more on the utility of the information contained in IB1 13 forms compared with SB2 extracts. There were problems with the number of IB1 13s returned by GPs and with the quality of many that were returned. Suggestions were made for tackling both these deficiencies in the current arrangements. In addition there were suggestions about revising the IB1 13 to increase its utility further.

Four ideas emerged for increasing the flow and quality of IB1 13s from GPs:

- Introduce payments for completion.
- Invoke management action for non-compliance.
- Introduce better quality control procedures.
- Introduce better training for GPs.

GPs are required to complete IB113 forms as part of their NHS terms of service and payment for this work is included as part of their overall NHS remuneration. This method of payment, through the GP's general salary, contrasts with the method of payment for some other medical reports, including other reports requested by the DWP. Requests for reports originating from the private sector, for example, from solicitors or insurance companies, usually generate a separate fee which is paid directly by the party requesting the report. One suggestion was to rationalise payment for all state social security benefit related reports and to pay an item of service fee for IB113 forms. It was suggested that such a direct fee could act as an incentive to some GPs. An alternative, but not mutually exclusive, view was to reaffirm that GPs have a contractual duty to complete IB113s and to invoke management procedures against GPs who consistently fail in that contractual duty.

In itself, it was recognised that increasing the number of IB113s returned was not sufficient. Quality also needed to be improved. This could be attempted by the introduction of quality control procedures that might, but need not, be linked either to a system of fees or management responses.

A different approach suggested was to introduce a better programme of training for GPs. This could include informing GPs of the importance to their patients of their contribution to the evidence gathering process for state benefits and educating them about the type and depth of information that is required from them. Factual evidence from the GP can make an important contribution to accurate decision making and the financial wellbeing of people can be a legitimate clinical concern. The aim of such a programme would be to encourage GP compliance and commitment, and to improve the quality of the information on IB113 forms. We have shown that some GPs take very seriously the task of completing IB113 forms for their patients. There may be lessons to be learned from such GPs about why and how they have this level of commitment which could be used in publicity or training to increase the commitment of other GPs.

There were several respondents who suggested that a review of the IB113 form itself was needed. We have shown above that many GPs find some sections or questions difficult to respond to. There were few specific suggestions for change but rather a more general feeling that if the form irritated or alienated some GPs then some reform was certainly appropriate. Two suggestions were that the IB113 should have more direct questions about functionality, and that there should be space for benefit or medical staff to add questions specifically relating to the individual claimant's circumstances. Suggestions such as these however would not in themselves address the criticism of some GPs that, in the course of treating patients, they do not necessarily accumulate knowledge about functionality.

### 7.3.2 Ideas based on the pilot arrangements

It was recognised that in the design of the pilot arrangements the problem of non-compliance (i.e. in relation to the completion of IB113 reports) among the GP participants, which undermines the current arrangements, is effectively eliminated. Suggestions for building on the pilot arrangements were therefore aimed more at increasing their operational effectiveness and efficiency. It will be apparent from the section on policy issues above that these suggestions would not command unanimous support from the research respondents in this study.

The range of ideas, which are largely self explanatory, included:

- handwritten extracts from GP records should be transcribed to overcome legibility problems faced by EMOs and decision makers;
- extracts in SB2 forms should be sorted chronologically according to condition, to assist and speed understanding by EMOs and decision makers;

- extracts should be annotated with explanations of difficult, obscure or unusual medical terms;
- the period for which information should be extracted, at least for new claims, could be restricted to one or two years;
- information should be sought where appropriate from other health, support and care professionals involved with the claimant.

It was recognised that the success of using GP records in incapacity benefit decision making depended largely on the quality of the raw material, but as we have mentioned earlier, GP records are very variable in quality. A suggestion for responding to this was that staff in Medical Services or Jobcentre Plus should be authorised to ask (or require) GPs to complete an IB113 in cases where the GP record was insufficient for benefit purposes.

### 7.3.3 Other ideas

One idea for improving clearance times of incapacity benefit was to combine the two stages that occur in the Medical Services Centre into one. At present, approved doctors handle some cases twice, first to provide advice about exemption, and for non-exempt cases, to provide advice a second time when the claim is scrutinised. In this process IB113s and Med 4 statements from GPs, or the GP records under the pilot arrangements, and IB50s from claimants, are requested at separate times.

A combined process would require GPs and claimants to supply information concurrently and thus save possibly several weeks in dealing with the claim. It was acknowledged that this would result in all claimants being asked to complete a Personal Capability Assessment, including people with severe physical and mental conditions who are currently not required to do so.

A different idea emerged from a reflection of developments in other areas of the welfare to work policy area. Current benefit and employment policy is aimed at helping as many people as possible into or back into work after a period of absence from the labour market because of sickness or disability. It is possible that services aimed towards the rehabilitation of claimants will increase as a result of the current policy direction. The records kept by rehabilitation services on individual clients, which can be expected to contain information about functionality, might therefore become an important additional source of information for benefit purposes.

## 7.4 Conclusions on research aims

The medical evidence gathering pilot was set up as a response to the known shortcomings in the existing arrangements for collecting and using medical information in making decisions on claims for incapacity benefit. In this section we return to the research aims that formed the starting point for this study and summarise the findings from the study, and offer some final reflections on developments in the future.

### 7.4.1 Impact on GPs

Few GPs said they had noticed any effect on their own work. Those who did notice a reduction in their workload included GPs in smaller practices, those whose practice received above average numbers of IB113 forms, and those who chose to spend time completing them fully. Generally these GPs welcomed the pilot for reducing the burden of paperwork.

The work of administering the pilot in the practice premises fell to practice managers and other administrative staff. The experience was variable, but for most it was unproblematic and manageable.

Practices adopting the photocopying option had experienced the greatest impact in terms of increased work, disruption of normal working schedules and financial impact.

Participating GPs were still generally in favour of the pilot arrangements when interviewed, and some non-participants were more favourably inclined towards the pilot after learning more about it from researchers and hearing about its impact in other practices. Some non-participating GPs still had serious concerns about confidentiality and informed consent. Other GPs maintained the view that they were the most appropriate people to provide medical information about their patients.

#### **7.4.2 Quality of medical advice given to decision makers**

In general, decision makers reported little impact on the quality of medical advice from approved doctors in Leeds or the EMOs in Medical Examination Centres. The nature of the information from approved doctors had changed and was generally more difficult to understand and not so useful as information contained in IB113 forms. Little change had been noticed in the quality of the IB85 medical reports from EMOs.

#### **7.4.3 Impact on decision making**

At each stage of the decision-making process the impact on decisions was felt to be small. There was a general view that benefit decisions on pilot cases would have been the same if made under the usual arrangements. Approved doctors perceived that at the scrutiny stage they had advised examination in a higher proportion of pilot cases compared with non-pilot cases. However, there was no evidence from this research to suggest that final benefit outcome decisions differed between the two groups.

There were, however, reports from some approved doctors, including EMOs, and decision makers that they had more confidence in some of the advice offered or decisions made on pilot cases because of the medical information available from SB2 extract of the GP records. Some EMOs also reported that they had been able to provide better informed advice about re-referral dates on some pilot cases.

#### **7.4.4 Overall effectiveness of the new procedures**

The procedures put in place for the operation of the pilot generally worked well in GP practices and the Leeds Medical Services Centre and the Medical Examination Centres. None of the GPs or practice staff reported problems with the procedures or had experienced difficulties when GP records were away from the practice premises. Sometimes this was due to the back-up procedures that the practices had introduced themselves. The courier firm used in the pilot was commended by some GP practice staff for its efficiency and professionalism. No problems with the collection or return of GP records were reported. In contrast, some staff in the Jobcentre Plus offices taking part in the pilot experienced difficulties, frustration and delays in implementing the mainly manual procedures used in the pilot.

### **7.5 Final comments**

The pilot was set up with two main objectives: to reduce GP workloads, and to improve the quality of incapacity benefit decision making. It was designed also to be acceptable to GPs and to incapacity benefit claimants.

From the evidence presented here the pilot appears to have had mixed results. Most of the GPs and claimants interviewed found the pilot arrangements acceptable in principle and workable in practice. Some holding this view still had some concerns but did not report any adverse experiences. In contrast, there were GPs and claimants who held strong and serious objections to the principle of the pilots. The

pilot, by its design, reduced the number of IB1 13 forms sent to GPs participating in the pilot. The effect at the level of the individual GP was only noticed in particular practices, some of which may be atypical in terms of their size and their internal working practices.

Among the users of medical information, approved doctors who prepared the SB2 extract were closest to the raw material of the GP records and found the information the most useful. At other stages of the process the impact of the pilot lessened. EMOs generally found the information interesting but it did not contribute greatly to their examination of claimants or their choice of descriptors. There was no consensus among the EMOs interviewed about which set of arrangements was preferable. For decision makers, the SB2 information was generally of less use than information on IB1 13s. This group of staff was the least in favour of the pilot arrangements, but some had difficulty expressing a preference between a system that generated useful information on only a minority of cases and a system that promised less useful information but on all cases.

This study has produced a range of findings, some of which were unexpected, and raised a number of important issues that must be taken into consideration in the development of incapacity benefit procedures in the future. Those issues have been mainly raised by GPs, claimants, and staff of Medical Services and Jobcentre Plus demonstrating the considerable interest in the pilot from all these groups. Other issues have arisen in the course of analysis. At the time of writing a consultation period on the reform of incapacity benefit has just ended. We can therefore expect that further policy ideas and changes about the administration of the benefit will be likely to attract a high level of attention and debate.

# Appendix A

## Research methods

### A.1 The pilot location

The pilot was conducted in the Sheffield and Rotherham area. This includes urban and rural settings with a range of socio-economic characteristics. Inner city and urban locations include areas with relatively high levels of benefit receipt; areas with high proportions of residents of minority ethnic background; and ex-industrial areas with relatively high levels of morbidity. Rural locations include ex-mining villages, and some higher income 'commuter' villages.

In the pilot area, most initial and ongoing claims for incapacity benefit are dealt with in the Sheffield and Rotherham Jobcentre Plus offices. Approved doctors who scrutinise the medical evidence supporting claims are based in Leeds; medical examinations are conducted in the Medical Examination Centres in Sheffield, Rotherham and Doncaster.

### A.2 Preparatory visits

Two preparatory site visits were undertaken, one to the Sheffield Jobcentre Plus office and one to Leeds Medical Services Centre. The purpose of these visits was to allow the research team to understand better the practice and procedures of the decision-making process under usual and pilot arrangements. The visits informed the design of the topic guide for all the groups interviewed. The visit to Sheffield Jobcentre Plus involved a meeting with the benefit manager for the medical referral team, two benefit processing staff and one decision maker. At the Leeds Medical Services Centre the research team met three members of the SchlumbergerSema project team; the operational manager; and two doctors engaged respectively in scrutiny, and medical examinations and training.



## A.3 Interviews with GPs and practice staff

### A.3.1 Building a study group

The aim was to conduct interviews with the senior or sole GP in 18 practices which had taken part in the pilot, and 12 practices which had chosen not to participate. The intention was to include men and women; a spread of ages among GPs; and a range of practice size (number of patients) and location, all of which might have some bearing on decisions to participate in the pilot, and experience of implementation.

An additional aim was to conduct interviews with key administrative staff in ten practices which had taken part in the pilot and whose GP was also interviewed.

Data supplied to SPRU for selection of a study group came in the form of one list of practices taking part in the pilot, and another list of those who were not. The lists included names and addresses of practices, and the names of the senior partner and other GPs in the practice. Also included for each practice was a name and telephone number for contact purposes, in most cases that of the practice manager or secretary. It thus proved not possible to determine a GP's age or number of patients in advance of selection, although the number of GPs attached to a practice gave some indication of relative size.

Initial study of the lists of GPs suggested that there were more large multi-practitioner practices among participants than non-participants, and conversely, that there were more single GP practices among the non-participants. It was eventually decided, therefore, to sample participant and non-participant GPs so that each sub-group included:

- men and women;
- practices in a range of locations, including urban areas known to have minority ethnic populations;
- some single practitioners;
- some senior partners in multi-practitioner practices.

The actual location of each practice listed was marked on a large scale map of the area. Using the above criteria, 30 practices were selected from 67 documented as taking part in the pilot; and 24 practices from 77 recorded as non-participants. SPRU sent letters to the senior or sole GP in each practice, inviting them to take part in a research interview. Included with this letter was a summary of the overall research design, and a further explanatory letter from the Department for Work and Pensions (in Appendix C). Letters were mailed in the first week of October 2002, and quickly followed up by telephone calls to arrange appointments. Permission to interview key administrative staff in participating practices was also sought during this telephone call, and arrangements made in advance or on arrival in the practice.

Achieving these interviews required some persistence. Some GPs were hard to reach and one or two had retired or died. A slightly higher proportion of GPs who did not take part in the pilot than those who did declined a research interview. Those GPs who preferred not to be interviewed generally said there were other priorities on their time. Two GPs who did not have time for an interview gave their views by telephone, and these discussions are included in the analysis. In four practices, the researcher was directed to the practice manager, as the person with the main responsibility for, and knowledge of, the pilot, who would represent the general views within the practice. Included here were some participating practices in which the GP had no initial recollection themselves of any pilot arrangements.

Altogether, interviews were achieved in GP practices as shown in Table A.1

**Table A.1 Recruitment of GPs and practice staff**

	Practices participating in pilot	Practices not participating in pilot
Practices notified to SPRU	67	77
Invitation letters sent	30 (31)*	24 (23)*
No contact made with named senior partner	11	8
Declined to take part	3	3
Interviews achieved:		
personal interview with GP	14	9
personal interview with practice manager, instead of GP	3	1
telephone interview with GP	-	2
personal interviews with additional practice staff	10	-

\* One GP from the non-participant list was discovered to be taking part in the pilot

The researchers used topic guides (copy in Appendix B) to steer discussions across the main areas of interest:

- characteristics of practice, and respondent;
- knowledge of the pilot, and views;
- reasons for taking part in the pilot, or not;
- effects of the pilot arrangements;
- experience of 'non-pilot arrangements' for supplying medical evidence;
- views on improving collection and use of medical evidence.

Personal interviews with GPs and practice managers on behalf of GPs generally took 30-45 minutes. Interviews with additional practice staff generally took slightly less time. An honorarium of £75 was paid to the senior partner in practices in which personal interviews were conducted. Personal interviews were tape-recorded, with permission, and transcribed for analysis.

The telephone interviews were fairly short, to suit the GPs, and the researchers made notes during the conversation.

### A.3.2 The study group: characteristics of GPs and practice staff

GPs in the study group included men and women, with different lengths of time in their current practice, and varying lengths of experience as a GP. Some were from minority ethnic backgrounds. The study group included four single practitioners, four GPs in two-partner practices, and several GPs in large practices with five or more partners, salaried GPs and a range of nursing/medical staff. All practices had at least two administrative/reception staff, and some large practices had more than 20 administrative/clerical and reception staff, often working part-time. One practice taking part in the pilot was operating from two sites.

The practices covered urban and rural areas in and around Sheffield and Rotherham, with a range of socio-economic characteristics. Some GPs reported relatively high levels of unemployment, social deprivation and morbidity among their patients; others said that their practice contained only small pockets of social deprivation, and employment was generally high. The study group included GPs practising in areas where many patients came from minority ethnic backgrounds.

Additional practice staff interviewed included practice managers, administrative staff and clerical/reception staff. This group included men and women.

## A.4 Interviews with Incapacity Benefit claimants

The aim was to talk to people who had agreed that their claim for incapacity benefit should be dealt with under the pilot arrangements **and** whose GP was participating in the pilot, and people claiming incapacity benefit who had declined to take part in the pilot. The decision was taken not to seek interviews with any incapacity benefit claimants whose GP had agreed to be interviewed for this qualitative research, for reasons of confidentiality and to encourage participation on both sides. This meant that sampling for recipients took place after deciding which GPs would be invited to take part in this research although the interviews with claimants actually took place before interviews with GPs and practice staff.

Developments in the implementation of the pilot affected the sampling strategy. Initially only claimants undergoing the PCA for the first time were included under the pilot arrangements, which began in January 2002. From April 2002 benefit recipients who were facing a second or subsequent PCA were recruited to the pilot, in order to boost the participant sample size. For purposes of description, we use DWP terminology and call the latter group (PCA) 're-referrals'.

The eventual aim was to achieve interviews with:

- 12 people making a 'new claim' who had agreed to take part in the pilot;
- 12 people facing a second or subsequent Personal Capability Assessment (re-referred) who had agreed to take part in the pilot;
- 12 people who had declined to take part in the pilot, of whom:
  - 6 were making a new claim; and
  - 6 were making 're-referred' claims.

It was known from previous research that has investigated claimants' views about how their claims are processed that people's assessments are often influenced by the outcome of their claim. The aim was thus to interview the incapacity benefits claimants before they received a decision. This required inviting recipients to take part in the research as soon as possible after the start of their claim. A flexible approach was required which enabled the research team to respond immediately to notifications by DWP of appropriate claimants, within an initially unspecified 'trawl' period, long enough for numbers to build of claimants going through the pilot.

The approach adopted was as follows. From May 2002 the DWP research management team sent to SPRU fortnightly lists of people claiming incapacity benefits in the Sheffield and Rotherham area. Claimants were distinguished according to whether they had agreed to take part in the pilot or not. Immediately on receipt of each list, letters of invitation from the DWP were sent from SPRU. The letters (Appendix C) reminded people about the trial to test new ways of getting medical information from their GP. It went on to invite them to take part in some research, to find out why they had decided to be in the trial, or not, and what they thought about medical records being used in this way. The opportunity was offered to opt out of the research, either to research managers in DWP or the SPRU research team secretary.

After two weeks, those people who had not opted out of the research were considered for inclusion in the study group. The researchers attempted to contact people quickly, mainly by telephone or

direct calls at their address. Some letters were also sent, inviting people to get in touch with the researcher to make an appointment. The latter approach was used when telephone contact was not possible.

The fieldwork continued in this way until the end of September, sending fortnightly waves of invitation letters followed up immediately after a two week opt-out period. A purposive study group was built as described in the following section.

### A.4.1 Building the study group

As described above, the aim was to recruit people who had and had not agreed to take part in the pilot; and people making new claims and those who had been re-referred, who had not yet received a decision about their claim. The researchers explained to those people contacted who had already received a decision that they were not among the group of people whom the researchers hoped to talk to. It was decided in advance that if any such people strongly wished to take part, interviews would be arranged for them. In the event, this was not necessary, although one or two people said they were disappointed not to be included.

Selection of people with home addresses across the Sheffield and Rotherham area led to the inclusion of patients from different practices. The researchers aimed to include similar numbers of men and women, with a spread of ages; to include people with a range of impairments and health conditions, and at least some people who had been assessed for Income Support or National Insurance credits (characteristics reported in the lists of names supplied to the research team). The aim was to include some claimants from minority ethnic backgrounds. People's names sometimes provided an indication here. An additional aim was to include people facing a Personal Capability Assessment for the first time and people who had had a previous experience, but it was not possible to select on this basis. Some of those making a 'new claim' (i.e. from a period of non-claiming) had claimed incapacity benefits in separate claiming spells, sometimes several years previously, which was not known to the researchers in advance of the interview.

### A.4.2 Response

It is not possible to report a 'response rate' in the way that is traditional in this kind of recruitment to research, for a number of reasons. Most important is that we do not know whether those who initially opted out or those who declined an interview when contacted by the researchers were actually in scope. Such people often explained quickly that they were too busy to take part or not interested in the research, and it was often then inappropriate to go on to ask them if they had received a decision about their claim. Thus, those declining an interview probably included a number of people whom the researchers would not have sought to include anyway. Indeed, people dissatisfied with the outcome of their assessment may have been less inclined to take part in the research, and those already in work may have had more constraints on their time.

An additional factor is that we do not know whether those people who had answerphones running when the researchers telephoned actually received messages left for them, inviting them to get in touch to arrange an appointment. Many people on the lists supplied had answerphones set up. Not replying to the researcher's message might have been a way of declining to take part in the research, so the researchers did not try again if two or three messages elicited no reply. It is also possible, however, that such messages just never reached the people for whom they were intended, for example, if a person had moved home, was in hospital or on holiday, or if somebody else in the household decided not to pass on the message. This also applies to recruitment attempted by letter.

We can make the following observations about the recruitment of incapacity benefit claimants for this study. A high proportion of the people listed were not accessible by SPRU by telephone. It was common for people to be ex-directory, probably related to increasing ownership of mobile telephones as well as preference for privacy. It was not unusual for telephone numbers listed by DWP to be out of use. It was not unusual for telephone numbers which were reached to have answerphones running, for what appeared to be large parts of the day and early evening. The researchers felt that this may be an indication that increasing numbers of people now choose not to answer their telephone immediately, even when at home, but to scan incoming calls and decide whether to respond.

Those people who did decline personally did not always give a reason. Some said they did not have time, as a result of work commitments or caring responsibilities; did not feel well enough; or preferred not to take part because they did not like meeting new people or answering questions. Some simply said they were not interested. Sending letters inviting people to get in touch with the researchers rarely resulted in an interview. Making a first contact by calling at a person's home was usually successful in terms of recruitment for an interview, but was resource intensive.

### A.4.3 Conducting the interviews

The researchers asked all those invited to take part where they would like to meet, and whether any special arrangements would make it easier for them to take part in the research. All preferred to be interviewed at home; some preferred to take part with their domestic partner. Nobody took part with an interpreter or signer. One interview was conducted by telephone because the person concerned preferred the researcher not to visit.

Topic guides (Appendix B) were used to steer discussion across the main topics of interest:

- Personal circumstances; employment and claiming histories.
- Awareness and understanding of pilot arrangements; reasons for taking part or not.
- Understanding of decision making processes in medical assessments.
- Previous (non-pilot) experience of medical assessments.
- Views on pilot arrangements.
- Views on medical examinations.
- Improving collection and use of medical information.

Interviews varied in length. Discussions were shorter when people had little awareness of, or interest in, the pilot arrangements or the general process of medical assessment for benefits purposes. If people were interested in the issues and had experiences they wanted to tell the researchers, interviews could take up to one hour and a half.

The discussions (including the telephone interview) were tape-recorded, with permission of respondents, and transcribed for analysis. Those who took part in the research received a gift of £20 to acknowledge their help.

#### A.4.4 Characteristics of the claimant study group

The study group of 32 people included 22 people recorded by DWP as taking part in the pilot arrangements, and ten people recorded as non-participants. According to DWP records, representation of people making 'new claims' and those who had undergone a previous medical assessment in their current claim, or been 're-referred', was as follows:

**Table A.2 Membership of the study group**

Pilot participants		Pilot non-participants	
New claims	Re-referred	New claims	Re-referred
12	10	7	3

The group included 21 men and 11 women, as shown in Table A.3. This largely reflected the composition of the sample supplied to SPRU. According to general administrative statistics supplied by DWP, 62 per cent of the incapacity benefit population in October 2002 were men.

The researchers initially aimed at a more equal balance between men and women in the study group, but there were fewer women who might be approached for interview, especially among people who had been re-referred.

**Table A.3 Men and women in the study group**

Pilot participants		Pilot non-participants	
Men	Women	Men	Women
14	8	7	3

The study group included people from all age ranges, as shown in Table A.4. In terms of comparison with the general incapacity benefit population, our study group had fewer people in the age range 50-59 years, and slightly fewer aged under 30 years.

**Table A.4 Ages of people in the study group**

	Pilot participants	Pilot non-participants
Under 30 years	1	-
30-39 years	7	3
40-49 years	6	3
50-59 years	4	2
60 years and over	4	2

People's family and household circumstances may influence their views about medical evidence and incapacity benefits. For example, claimants may have discussed with a partner whether to take part in the pilot; or responsibility for dependent children may influence people's views on the outcome of a Personal Capability Assessment. Table A.5 shows the family and household circumstances of claimants in the study group. Fifteen of the claimants were owner-occupiers; 12 local authority tenants; four had private landlords and one was a housing association tenant. One person had a minority ethnic background.

**Table A.5     Family and household circumstances**

Lives with partner	11
Lives with partner and dependent children	7
Lone parent	2
Lives with partner and adult relatives	4
Lives with adult relatives	1
Lives alone	6
Lives with person as their carer	1

**A.4.5     Health and impairment**

The aim was to achieve a study group which included people from a number of broad categories of health conditions and impairments. Most people interviewed talked about current health circumstances or impairments which affected their capacity to work. People often spoke of a number of different aspects of current ill-health which affected daily living in a number of different ways. One example was managing limited mobility due to severe arthritis at the same time as dealing with clinical depression. We made no attempt to categorise people in the study group in terms of diagnoses of illness, or type of condition. As a result of what people told us, however, we know that the study group included people with musculo-skeletal conditions; respiratory and circulation problems; multiple injury; epilepsy; diabetes; sensory impairment; different kinds of mental illness (depression, anxiety, phobias, psychosis); cancer and other progressive illnesses; and drugs or alcohol dependence.

The Sheffield/Rotherham area has a history of industrial and mining employment, and there are still some areas of concentration of heavy industry and manufacturing. As we might expect, some of the men in the study group had experienced serious industrial accidents and injury.

In some cases, symptoms of current illness affected the conduct of the interviews. For example, some people were distracted by pain or fatigue. Some found it hard to maintain discussion, due to severe depression, and some became tearful and needed time to re-engage with the interviewer. One person's views were possibly affected by paranoia. Some people explained poor recall of events and lack of concentration in the interview as due to effects of powerful medication, brain injury or stroke. In all such cases, the interviewers did as much as possible to prevent the interview being a negative experience, and this sometimes meant not pursuing issues which were sensitive, or conducting a shortened interview. We have taken account of the above factors in the analysis. Material from all the interviews was valuable.

**A.4.6     Employment and benefits**

In terms of benefit receipt and entitlement, most people were being assessed for incapacity benefit when selected for the study group. The group also included some people who had been claiming Income Support with a disability premium because they had insufficient contributions for eligibility for Incapacity Benefit. A number of people were also receiving industrial injuries allowances, and the study group included recipients of Disability Living Allowance. Not everybody was certain which benefit they were claiming, however, and it is not possible to present a systematic analysis of benefit receipt. Although the aim had been to interview only people who had not yet received a decision in their current claim for incapacity benefits, it appeared that a few respondents had actually been told the decision by the time they met the researcher.

There was a wide range of views about the possibility of returning to paid employment. Those who thought returning to work was unlikely included:

- people who said that their hospital consultant had advised not to go back to work;
- people facing a progressive illness or deteriorating condition;
- people very close to retirement age.

Those most keen to return to work included people responsible for children and people who had a long employment history and disliked the inactivity and boredom involved in being away from a workplace. Included in the latter group were some of the oldest men interviewed. By the time of the interview, one man was about to start work using permitted work rules; another was considering a job offer, and another had started applying for jobs. A person who had just been told that his incapacity benefit was going to be withdrawn, after a Personal Capability Assessment, said he was resigned to having to look for a part-time job.

Two women still had contracts of employment and hoped eventually to return to their employer, perhaps with an adjustment of activities at work. Two of the younger members of the group were aiming towards higher education rather than paid work, when their condition improved.

## A.5 Group discussions with incapacity benefits processing staff

In discussions with the appropriate line managers in the Sheffield and Rotherham Jobcentre Plus offices it was possible to identify all staff involved in some way in the processing of incapacity benefit claims. Managers were asked to nominate staff who could attend and contribute to a group discussion on the basis of having a reasonable amount of experience of the pilot arrangements. It was recognised that organising the release of staff from busy sections might cause some disruption so no other selection criteria were imposed.

The discussions with processing staff took place in mid-November 2002, when the pilot had been running for nearly one year. There were three discussions, in different Jobcentre Plus offices in Sheffield and Rotherham. Altogether, ten members of staff took part, all but one of whom were women. All were administrative officers, engaged solely or partly with medical administrative work, and most had been in post throughout the lifetime of the pilot.

One researcher moderated each discussion, using a guide (Appendix B) to steer discussion across the topics of interest:

- Practice in processing claims: pilot and non-pilot arrangements.
- Impact of pilot arrangements.
- Strengths and weaknesses of pilot arrangements.
- Suggestions for improvement.

The group discussions worked well. Respondents from each different office generally worked together as a team, and were used to sharing their views in a group setting. The discussions were tape-recorded, with permission, and transcribed for analysis.



## A.6 Discussions with decision makers

All decision makers working on incapacity benefit claims were identified in discussions with the appropriate managers in the Sheffield and Rotherham Jobcentre Plus offices. The intention was to include, in this phase of the research, all decision makers apart from the person who had already participated in the research in site visit discussion earlier in 2002. Managers were asked to nominate two officers from their respective offices to take part in a group discussion. Other decision makers would be asked to participate in a one-to-one interview.

Six decision makers were thus interviewed individually and four took part in the group discussion. Over the course of the research, therefore, all decision makers working on pilot cases took part in the research. Fieldwork was carried out in November 2002. One member of the research team moderated the group discussion.

The aim of the one-to-one interviews was to explore individual practices and experiences of making incapacity benefit decisions under both the pilot and the usual arrangements. In contrast, the group discussion was used to explore what medical information decision makers need to do their job and to think about how this might be organised in the future. Topic guides are included in Appendix B.

Topics covered in the individual interviews included:

- The role of the decision maker.
- The impact of the pilot arrangements.
- Strengths and weaknesses of the pilot arrangements.

Topics covered in the group discussion included:

- Information needs of decision makers.
- Views about collecting medical information in the future.
- Preferences for working with usual arrangements or pilot arrangements.

Both the individual interviews and the group discussion worked well. All discussions were tape-recorded, with permission, and transcribed for analysis.

## A.7 Interviews with Medical Services staff

Interviews with approved doctors in the Leeds Medical Services Centre were organised through the operational leader with responsibility for administering the pilot. All four doctors who were in post and carrying out work connected with the pilot in November 2002 were interviewed. Interviews with Examining Medical Officers (EMOs) were arranged through the manager of the Sheffield Medical Examination Centre. All six of the EMOs who were seeing pilot cases regularly were interviewed. In agreement with DWP, one EMO, who had seen only two claimants under the pilot arrangements, was not interviewed. An interview with the operational manager for the pilot was arranged directly with her.

A single topic guide (see Appendix B) was used in the interviews with approved doctors in Leeds and with EMOs. The researcher used appropriate sections according to the role of the individual being interviewed. Topics covered included the following:

- Background and experience.
- Extracting information from GP records.
- Experience of making decisions about exemption.
- Experience of carrying out the scrutiny stage in the decision making process.
- Experience of carrying out medical examinations.
- Views about how medical information could be collected in the future.

Topics covered in the interview with the Medical Services Centre operational manager included:

- Impact of the pilot arrangements.
- Strengths and weaknesses of the usual and pilot arrangements.
- Lessons learned from the pilot for the future administration of incapacity benefit claims.

All interviews with Medical Services staff worked well. Discussions were tape-recorded, with permission, and transcribed for analysis.

## A.8 Analysis

Analysis of material from each part of the research was handled separately, but the approach was similar in each case. Analysis began with reading the transcripts or tape-recordings and additional fieldnotes, and arrangement of material under key headings, reflecting the main topics for enquiry and additional themes emerging from the data. A series of thematic charts was drawn up, for each set of transcripts, and data from each transcript summarised under the appropriate heading.

The method has been developed and refined within SPRU over many years, alongside the 'Framework' approach (Ritchie and Spencer, 1994) initiated by Social and Community Planning Research, now the National Centre for Social Research, which takes a similar analytic approach in the context of conducting applied qualitative research.

Ordering data in this way means that, in the case of interviews with individuals, the accounts of all respondents can be explored within a common thematic framework, grounded in the data collected. It helps to highlight the full range of perceptions, beliefs, experiences and behaviours described by the respondents, and enables exploration of the factors which underpin them. The method enables within-case and between-case analysis, essential for drawing out a full interpretation of the data. The final stage of the analysis involves reviewing the data mapped in the thematic matrix; comparing accounts from individuals, and identifying patterns and explanations within the data. A similar approach was taken with analysis of transcripts from group discussions, which identified contributions from individual members of the groups.



# Appendix B

## Topic guides

### TOPIC GUIDE

#### Interview with participating GPs

##### Interviewer's introduction

*You were invited to take part in this research because you/your practice are participating in the Department for Work and Pensions trial to test a new way of collecting information for deciding whether people are eligible for incapacity benefits. We would like to hear about your views and experience of the trial.*

- Remind about SPRU
- Explain the issues to be covered
- Discussion will last around one hour
- Explain confidentiality, and how the material will be used
- Ask for permission to use tape-recorder
- Any questions or concerns?
- Give money gift.

##### 1. Employment history, information about practice

- Time as GP
- Time in this practice
- Number of GP sessions/week

*(Ask multi GP practices only)*

- 'Personal list' of patients or 'shared practice list'
- Number of patients (practice, self)

##### 2. Knowledge of trial

- How did you learn about the trial?
- How was rationale for trial explained?
- How is the trial being conducted?
  - what gets sent, to whom
  - what happens to information
  - how quickly are notes returned
- Views about patients' notes being used in this way

##### 3. Reasons for taking part in the trial

- Initial view
- How was it decided?
  - involvement of colleagues, practice staff
- Decision to send case files or photocopies
  - Explore

##### 4. Effects of trial

- On workload
- On administration of the practice
  - extra work? for whom?
  - costs?
- Any impact on patient care and on ability to do own job
- On relations with patients who are claiming a state benefit
- Have they been contacted by Medical Services doctors in Leeds/Sheffield to discuss administrative aspects of the trial, or individual patients in the trial?
  - reason? views.
- Are arrangements for transporting notes and returning them working smoothly?
  - how could difficulties be overcome?
- Any feedback from individual patients?

##### 5. Experience of usual arrangements

- [NB GPs will still be filling in some IB113s for claimants who opted out of the trial]
- How many medical statements (e.g. Med 3) do you usually issue each week? How many of these are for people with ongoing disabling conditions?
- How many (or what proportion) of your patients do you think are currently in receipt of a state incapacity benefit?
- Overall how much work does benefit related work usually amount to for you each week (on medical statements, medical reports and related appointments with patients)?
- What is the process of completing IB113?
  - dealing with IB113 in practice
  - any guidance available/used
- Views about filling in form IB113
  - time taken per week
  - any questions that GPs find particularly difficult to answer
  - Probe: what is difficult

- Does more information go into the IB113 than is accessible in the patient's notes? *Probe*
- How far do you think the information you provide on the IB113 can influence the outcomes of claims?
- Do you form a view about whether patients should receive IB?
- Are there any advantages or disadvantages in completing a statement that is handed to the patient, like a Med4, compared with an IB113 which the patient does not see?

#### 6. Comparison with similar arrangements

- Usually, in your practice, are patients' notes used by anyone else outside the practice?  
     who? for what purpose?  
     views about patient notes being used in this way

#### 7. Improving collection and use of medical information for deciding incapacity benefits

- Knowing what you know now, would you have participated in the trial?  
     *Probe for reasons*
- How would you feel about it being introduced across the country as the new way of collecting clinical information on all patients who are on a state incapacity benefit?  
     *Probe*
- Are new arrangements appropriate for all incapacity benefit claimants or some only?  
     *Probe*
- How best do you think factual information about your patient's condition could be obtained to inform benefit assessments?

### TOPICGUIDE

#### Interviews with office staff of participating GPs

#### Interviewer's introduction

*You were invited to take part in this research because you/your practice are participating in the Department for Work and Pensions trial to test a new way of collecting information for deciding whether people are eligible for incapacity benefits. We would like to hear about your views and experience of the trial.*

- Remind about SPRIU
- Explain the issues to be covered
- Discussion will last 10-15 minutes
- Explain confidentiality, and how the material will be used.
- Ask for permission to use tape-recorder.
- Any questions or concerns?

#### 1. Background information

- Position/job title
- Other office staff
- Roughly, how many cases have been dealt with under trial arrangements?
- Is practice (a) sending case notes; (b) sending photocopies; (c) sending notes electronically?
- were staff involved in the decision of the practice to take part in the pilot?

#### 2. Effects of trial

*Interview note: adapt questions accordingly for different means of supplying information.*

- What is the procedure for handling requests for notes?  
     how does request come to you?  
     who does what?  
     do you have to make any decisions/judgments about what to send?  
     *Probe*  
     how quickly can request be dealt with? Is it a priority task?  
     are GPs involved in any way?
- How do you keep track of notes?  
     explore manual/computer systems  
     how quickly are notes returned?  
     do you chase (late) returns?

- Are arrangements for transporting notes and returning them working smoothly?  
how could difficulties be overcome?
- Has trial had any effect on patients? *Probe*
- Has trial created any problems for you? *Probe*
- Overall, has the trial created much extra work? *Probe*
- Views about sending only a portion of the casenotes
- Any issues of confidentiality arising from pilot arrangements?
- Any suggestions for improving trial arrangements?

## TOPIC GUIDE

### Interview with participating clients

#### Interviewer's introduction

*You were invited to take part in this research because you have recently made a claim for incapacity benefits in the Sheffield/Rotherham area. In this area the Department for Work and Pensions is trying a new way of collecting information for deciding whether people are eligible for incapacity benefits. We would like to hear what you think about this.*

- Remind about SPRIU
- Explain the issues to be covered
  - about you and your household
  - about your recent (or continuing) claim for incapacity benefit (for which a decision is still awaited)
  - thoughts about the trial (whether you are taking part or not)
  - experiences of claiming incapacity benefit in the past
  - views about medical examinations (whether or not you have had one)
  - your ideas about how to improve how your claim is dealt with (might want to bear this in mind as we proceed)
- Discussion will last around one hour – check need for breaks
- Explain confidentiality, and how the material will be used
- Explain discussion will have no effect on current claim, on any other benefits, or dealings with DWP, Inland Revenue, Employment Service, Child Support Agency etc., or any dealings with your own GP
- Ask for permission to use tape-recorder
- Any questions or concerns?
- Give money gift.

#### 1. Personal circumstances, employment history, claims history

##### Details of household

- household members; age
- responsibility for children
- tenure

## Employment/benefit history

(to explore experience of paid work and sickness/incapacity benefits, focusing on last two to three years)

- periods of employment; type of work
- claims for sickness/incapacity benefit
  - route onto IB (including type of illness/impairment)
- receipt of other benefits
- attempts to try/return to paid work
- current situation in respect of work and health

## 2. Awareness of taking part in the trial

[Interviewer note: Ask following question about awareness of being in the trial and route to appropriate set of questions. Refer to claim form if necessary to remind claimant how agreement to take part was sought.]

**Are you taking part in the trial testing the new way of collecting medical information for benefit claims using GP medical records?**

- If yes – go to section 3a
- If no – go to section 3b
- If don't know – go to section 4

## 3. Experience before taking part in the trial

### 3a. Ask participants

**Was it clear to you what taking part in the trial would mean?**

- understanding what the trial involved
  - aware that participation was voluntary?
  - aware that GP involvement was voluntary?
  - views on GP participation
  - usefulness of DWP information (leaflet/letters/claim forms)
- perception of impact for self
  - did you think it would affect decision on claim?
- perception of impact for GP; administrative staff
- feelings about taking part – interest/curiosity; positive/negative feelings

**Overall, what made you decide to agree to take part in the trial?**

**Now go to Section 4.**

### 3b. Ask non-participants

**Was it clear to you what taking part in the trial would mean?**

- understanding what the trial involved
  - aware that participation was voluntary?
  - aware that GP involvement was voluntary?
  - views on GP participation
  - usefulness of DWP information leaflet?
- perception of impact for self
  - did you think it would affect decision on claim?
- perception of impact for GP; administrative staff
- feelings about taking part – interest/curiosity; positive/negative feelings

**Overall, what made you decide NOT to take part in the trial?**

**Now go to Section 4.**

## 4. Understanding of decision-making processes for recent claim/medical assessment

[Interviewer note: refer to trial arrangements for respondents who have answered Section 3. Do not mention trial for others.]

**We are interested to know whether it's clear to people how their entitlement to incapacity benefit is dealt with. Thinking about your [most] recent dealings with DWP about your incapacity benefit, can you tell me what happened [after you sent in your claim form]/[when your claim form was looked at again]?**

*Seek unprompted answers and observations first. If necessary, prompt:*

- How do you think GP has been involved?
  - what sort of information has he/she provided to DWP?
- How have local benefit office been involved?
- Anyone else (e.g. special doctors, advisors) involved? How?

**Who do you think might be involved in the next few weeks or months? How will they be involved?**

*Prompt again for GP and others' involvement*

**What sort of information do you think benefits staff need about your illness or condition and how it affects your working?**

- Kind of information
- Source of information
- How is information collected? Forms/letters, medical examinations

**How sensible does that way of collecting and using information about you seem, for deciding your entitlement to incapacity benefit?**

- Perceptions
- Beliefs and feelings
- Concerns and anxieties

**5. Check for previous claims/ medical assessments to decide Incapacity Benefit entitlement**

**We have talked about your recent claim, but can I check whether you have put in a claim for Incapacity Benefit in the past?**

If yes – go to Section 6

If no – go to Section 7

If don't know – go to Section 7

**6. Previous experience of [claiming/having an assessment for] Incapacity Benefit**

*[Interviewer note: Some respondents will be re-referral claimants. We are interested in their views on how their medical test was dealt with on the most recent occasion before the trial started. Other respondents will be talking about medical tests in respect of separate past claims.]*

**Can I check about when you last had a medical assessment(s) for incapacity benefit?**

**Can you say how last time was different to this time?**

- how was GP involved?
- how was local benefit office involved?
- how was anyone else (e.g. special doctors, advisors) involved?

**What sort of information was collected that time?**

- kind of information
- source of information
- how was information collected? forms/letters, medical examinations

**In your view, how sensible was *that* way of collecting and using information?**

- perceptions
- beliefs and feelings
- concerns and anxieties

**7. Deciding entitlement under the trial arrangements**

**I now want to ask (more) questions about the new arrangements for collecting medical information under trial in the Sheffield/Rotherham area.**

**May I just run through what is happening in the trial?** *Interviewer explain.*

**Do you know what information is kept in GP records?**

*Seek unprompted answers first. If necessary, prompt:*

- GP's own notes
- hospital letters
- test results

**Do you think there are advantages in using the actual medical notes in deciding your entitlement to incapacity benefit?**

*Probe for:*

- perceived advantages for self
- better decisions
- speed/ease of process

**Do you think there are any disadvantages?**

*Probe for:*

- perceived disadvantages for self
- concern about what information notes contain
- not such good decisions
- speed/ease of process

**We want to talk about the way in which the new arrangements affect GPs, but can I first ask about you and your GP?**

*Explore:*

- length of time with GP
- recent contact; nature and extent of GP involvement; same/different GPs
- other medical treatment
  - attendance at hospital/clinic
  - awaiting treatment?
- generally good/not good relations with GP
- confidence in GP
- extent to which GP knows about their work aspirations



**Do you think that if the new arrangements were introduced for all claims your relations with your GP would be affected in any way?**

*Explore:*

- improving relations
- increased pressures/tensions

#### **8. Medical examinations**

**Some people are asked to go for a medical examination as part of deciding their entitlement for incapacity benefits. Have you had a medical examination for your new, recent claim?**

**If yes, probe for experiences and views**

- Knowledge of information available to examining doctor
- Extent of doctor's knowledge about condition, and its effects on daily living and ability to work
- Did doctor refer to medical records?
- Differences from other medicals, i.e. for other benefits?
- Views on whether doctor should have report from GP, or extracts from notes made by DWP doctor.

*Probe for reasons.*

**Now ask all**

#### **Views on medical examinations**

- What kinds of people are asked to go for a medical examination
- What kinds of circumstances
- Appropriateness for finding out how illness/condition affects ability to work

*Probe for reasons*

- Appropriate role for GP notes in medical examinations

*Probe for reasons*

- Should every claimant have an examination?

#### **Respondent's preferences**

*Ask claimants who have NOT had an examination (yet)*

- Would you like to have a medical examination in connection with your claim?

*Probe for reasons*

*Ask claimants who HAVE had an examination*

- Would you have preferred NOT to have had a medical examination?

*Probe for reasons*

#### **9. Improving collection and use of medical information for deciding incapacity benefits**

**Now that we have talked about this trial in detail, do you think it is a good idea?**

- Perceived advantages
- Perceived disadvantages
- Remaining concerns/anxieties

**Knowing what you know now, would you have participated/not participated in the trial?**

*Probe for reasons*

**How would you feel about it being introduced across the country as the new way for dealing with everybody's applications for incapacity benefits?**

*Probe for reasons*

**Have you any suggestions for better ways of deciding people's entitlement to incapacity benefit?**

**Thank you for taking part.**

## TOPIC GUIDE

### Group Discussion with Jobcentre processing staff

#### Interviewer's introduction

*You were invited to take part in this research because you play a central role in the Department for Work and Pensions' pilot to test a new way of collecting information for deciding whether people are eligible for incapacity benefits. We would like to hear about your views and experience of the pilot arrangements. We are particularly interested in any comparisons you can make between the pilot arrangements and the 'usual' arrangements you are still using where GPs or claimants have opted out of the pilot.*

- Remind about SPRU; remind about earlier visit to Sheffield Jobcentre in May
- Explain the issues to be covered
- Discussion will last around one hour
- Explain confidentiality, and how the material will be used
- Ask for permission to use tape-recorder
- Any questions or concerns?

#### 1. Identifying differences in practice under the pilot arrangements

- We want first to identify the differences in what you actually do in processing claims under the pilot arrangements compared with the 'usual' arrangements. At this stage we are not trying to assess whether these have had positive or negative effects. That will be the next task.

*Interviewer note: try to identify and distinguish (a) new activities they do, (b) things they do not do under the pilot arrangements, and (c) things they do differently.*

#### 2. Impact of pilot arrangements

- Now we want to talk about what effects these changes have had, for example how they have made your job easier (or not), and what problems (if any) have arisen.

*Interviewer note: use prompts if required.*

*Prompt: Have you had to deal with any major difficulties/bottlenecks in processing claims? How did you respond?*

*Prompt: Has there been an impact on*

- speed of processing?
- number/type of appeals

*Prompt: How have contacts with other key actors been affected?*

- other Jobcentre staff
- Medical Services doctors
- GPs
- claimants
- others?

*Prompt: Has anyone from the above groups raised any concerns about the pilot arrangements?*

*Prompt: Do processing staff have any concerns?*

#### 3. Follow up of points from early site visit in May 2002

- It was very early days when we visited in May, but some points were raised that we would like to follow up.
  - IT support
  - apparent simplicity of pilot, compared with actual experience
  - effect of performance targets

#### 4. Lessons from pilot

- What are the main strengths? *Probe fully (compare with usual arrangements)*
- What are the main weaknesses/area of concern? *Probe fully (compare with usual arrangements)*
- Suggestions for improving process?

### TOPIC GUIDE

#### Interview with Medical Services Operation Manager

##### Interviewer's introduction

*You were invited to take part in this research because you/your practice are participating in the Department for Work and Pensions trial to test a new way of collecting information for deciding whether people are eligible for incapacity benefits. We would like to hear about your views and experience of the trial.*

- Remind about SPRIU
- Explain the issues to be covered
- Discussion will last around one hour
- Explain confidentiality, and how the material will be used
- Ask for permission to use tape-recorder
- Any questions or concerns?

##### 1. Impact of pilot arrangements

- What have been the main differences in processing pilot and non-pilot cases?  
*probe: speed*
- What determines the flow of work to the doctors?
  - are certain types of case reserved for particular doctors?
  - impact? e.g. speed of processing
- How has Tracker system of case control worked? Have any useful lessons emerged?
- Do you organise the collection of additional information when requested by approved doctors?  
*probe: who, how often, response rate, timing*

##### 2. Lessons learned from the pilot

- What have been the main strengths and weaknesses of the pilot arrangements?
- How could processing of cases be quicker?

### TOPIC GUIDE

#### Interviews with approved doctors

##### Interviewer's introduction

*You were invited to take part in this research because you play a role in the Department for Work and Pensions trial to test a new way of collecting information for deciding whether people are eligible for incapacity benefits. We would like to hear about your views and experience of the trial.*

- Remind about SPRIU
- Explain the issues to be covered
- Discussion will last around one hour.
- Explain confidentiality, and how the material will be used.
- Ask for permission to use tape-recorder.
- Any questions or concerns?

##### Interviewer note:

Medical practitioners play a variety of roles in the administration of incapacity benefit. These are referred to in this report as *approved doctors*. The key role of the *approved doctor* in the Medical Evidence Gathering Pilot included

- preparing a data extract from GP case files (on form SB2),
- advising decision makers on paper evidence for exemption/scrutiny cases,
- advising decision makers following an examination of the claimant (when they act as an Examining Medical Officer (EMO)).

Ask questions in Sections 2 and 3 accordingly.

##### 1. Background/medical experience

- Current role
- Number of sessions
- Other (concurrent/previous) employment
  - Experience of General Practice (no. of years; years since working as GP)
  - Specialisms/areas of expertise

## 2. Extracting information from GP notes

- Is the process of extraction the same for (a) exemption stage and (b) scrutiny stage?

*Probe for differences*

- How do you identify 'relevant information' as defined in the context of a claim for incapacity benefit for (a) pilot and (b) non-pilot cases? *Probe for differences.*
  - how do you decide what to include/exclude on the SB2 form?
- How easy/difficult is it to extract relevant information?
  - what makes a case 'easy' or 'difficult'?
- How variable are GP notes?
  - do they contain relevant information of value to the issues for which an approved doctor has to provide advice?
  - what information, if any, is missing?
- Do you ever need further information other than what is in GP notes?
  - What do you do in such circumstances?
- Any comments on design of form SB2?

*Probe*

- Is there a difference between handwritten and computerised GP notes?

*Probe for differences and impact/legibility*

- How long does extracting information take? *Probe for range of times*
  - is this a problem? *Probe*

## 3. Experience of exemption and scrutiny

### (a) Exemptions

- Experience of EXEMPTION cases in the pilot (no. of cases; frequency)
- Experience of NON pilot cases (no. of cases; frequency)
- Comparison between pilot and 'usual' arrangements
  - what information is available under 'usual' arrangements?
  - do you need to contact GP for any reason? *Probe*
  - in pilot, how much of GP notes do you need to refer to? (e.g. no. of years)
  - is it easier to decide exemptions under pilot? *Probe for reasons*
  - have you made *more* exemption decisions in the pilot?
  - do you find that the evidence from the GP notes has helped to increase your level of confidence in the advice given (to exempt or not)? *Probe*
  - time needed for exemption cases
  - has task changed for some types of case more than others? (e.g. type of disability)? *Probe for examples*
- How would you summarise the relative pros and cons of using GP notes compared with 'usual' arrangements? *Probe fully*

### (b) Scrutiny

- Experience of SCRUTINY cases in the pilot (no. of cases; frequency)
- Experience of scrutiny of NON pilot cases (no. of cases; frequency)
- Comparison between pilot and 'usual' arrangements
  - what information is available under 'usual' arrangements?
  - do you need to contact GP for any reason? *Probe*
  - how much of GP notes do you usually need to refer to? (e.g. no. of years)
  - are there cases where five years is *not* enough? *Probe*
  - is it easier to give clear/unambiguous advice (i.e. to pass or not pass the case) under pilot? *Probe for reasons*
  - Compared with non-pilot cases where an IB 113 or Med 4 is available, has number of cases where there is insufficient information to decide fallen?
  - Using the information from the GP notes, are you more confident about the advice you give (to accept or call for exam)? *Probe*
  - how long does process take? any preference compared with standard scrutiny work?
  - has scrutiny task changed for some types of case more than others? (e.g. type of disability)? *Probe for examples*
- How would you summarise the relative pros and cons of using GP notes compared with using (a) IB113s and (b) Med4s? *Probe fully*
- 'Rework' claims - has pilot affected number, type, content of 'rework claims? *Probe fully.*
- Views about practice staff being used to draft IB113s.

## 4. Medical examinations

- What has been the effect on the task of examining claimants of replacing the IB113 or Med 4 with the SB2?
- In what way is information in SB2 different to information in non-pilot cases? *Probe fully for advantages and disadvantages of differences.*
- How is information on SB2/IB113/Med4 used? *Probe for differences*
  - before the examination (in preparing to see claimant)
  - during the examination (e.g. discussing contents with claimant)
  - afterwards in completing the IB85?
- Views on having copied extracts from GP notes in SB2 *Probe for pros/cons. Compare with information from scrutiny doctors.*
- Explore perceptions of:
  - differences in content/depth of information on IB85
  - confidence in their advice recorded on IB85, e.g. on functional ability and re-referral period

- Explore perceptions of differences in type of case being referred for examination. *Prompt:*
  - more/fewer cases seen at examination that are clear exemptions?
  - more/fewer cases seen at examination that are 'obvious' allowances or disallowances?
- Preference for new or 'usual' arrangements?
- How could the pilot arrangements be changed to be more useful?
- How could the 'usual' arrangements be changed to be more useful?

#### 5. Improving collection and use of medical information for deciding incapacity benefits

- What is the most suitable time period for GP notes (to balance need for all relevant information, administrative efficiency, and client confidentiality)? *Probe*
  - any difference for referral and re-referral cases?
- Are GP case notes or current arrangements more likely to enable Medical Service doctors to gain a clear and accurate picture of a claimant's level of incapacity?
- How would you feel about arrangements to use GP case notes being introduced across the country as the new way of collecting clinical information on incapacity benefit claimants?

*Probe for reasons*

- Are new arrangements appropriate for all incapacity benefit claimants or some only?

*Probe*

- How best do you think factual clinical information about the claimant/ patient's condition could be obtained to inform benefit assessments?

#### TOPIC GUIDE

##### Interviews with Jobcentre Plus decision makers

#### Interviewer's introduction

*You were invited to take part in this research because you play a central role in the Department for Work and Pensions' pilot to test a new way of collecting information for deciding whether people are eligible for incapacity benefits. We would like to hear about your views and experience of the pilot arrangements. We are particularly interested in any comparisons you can make between the pilot arrangements and the 'usual' arrangements you are still using where GPs or claimants have opted out of the pilot.*

- Remind about SPRIU
- Explain the issues to be covered
- Discussion will last around one hour
- Explain confidentiality, and how the material will be used
- Ask for permission to use tape-recorder
- Any questions or concerns?

#### 1. Role of decision maker

- What is your role in deciding:
  - exemption cases,
  - cases passed on scrutiny,
  - medical examination cases?
  - Who else is involved?
- Roughly how many cases have you dealt with under the pilot arrangements?
- In general, how easy is it to make decisions on Personal Capability Assessments? What are the main issues and areas of concern/difficulty?
- How frequently do you find yourself coming to a different conclusion to an approved doctor on a case?
  - under what circumstances is that most likely to happen?

## 2. Impact of pilot arrangements

*[Interviewer note: Explore differences between pilot and 'usual' arrangements on the following aspects of decision makers' work. Probe responses fully.]*

- speed and efficiency of processing
  - time needed
  - number of cases returned to Medical Services for 'rework'
- process of decision making
  - need to contact others (e.g. other Jobcentre staff; approved doctors; GPs; claimants; others)
  - need to consult guidance/reference material
  - are pilot arrangements particularly suitable or unsuitable for certain kinds of case? *Probe for type of case where GP notes/SB2 particularly useful*
- quality of medical evidence
  - changes in content/depth/clarity of medical advice from approved doctor
  - has quality of the examining doctor's advice improved on the IB85?
  - do you agree or disagree more with the approved doctor's advice on the IB85 report? Why?
- quality of own decisions
  - are your decisions 'better' in any way? *Probe*
  - do you have more confidence in own decisions? *Probe for reasons*
  - is new approach to evidence gathering likely to have any impact at the appeal or re-consideration stage?
  - is supporting advice/guidance material sufficient? *Probe for gaps/weaknesses*
- Has the impact of the pilot been different for new and re-referral claims? *Probe fully.*

## 3. Overall view of pilot arrangements

- What are main strengths? *Probe fully (compare with usual arrangements).*
- What are main weaknesses/area of concern? *Probe fully (compare with usual arrangements).*
- Suggestions for improving process



# Appendix C

## Letters





**DWP** Department for  
Work and Pensions

Our address	Social Research Branch Department for Work and Pensions 4 <sup>th</sup> Floor The Adelphi 1-11 John Adam Street London WC2N 6HT
Our phone number	0207 962 8003
Our fax number	0207 962 8542
Email	jo.bacon@dwp.gsi.gov.uk
Website	<a href="http://www.dwp.gov.uk/asd/">www.dwp.gov.uk/asd/</a>
Date	4 October 2002
Reference	

Dear

### **Evaluation of Medical Evidence Gathering for Incapacity Benefit pilot**

I am writing to ask for your help with this important research study.

As you may know, the Department for Work and Pensions (DWP) is piloting a scheme with GPs and benefit clients in the Sheffield and Rotherham areas that involves collecting medical evidence for Incapacity Benefit claims directly from patients' case notes.

In order to evaluate the pilot, the Department has appointed the Social Policy Research Unit (SPRU) at York University to undertake qualitative research with the various groups of people who were invited to take part in the scheme, including those General Practices which decided not to take part. These face-to-face qualitative depth interviews will allow the researchers to fully explore the views of non-participating practices, which will be important in helping us to gain a fully rounded assessment of the pilot.

The value of the research depends on the willingness of practices and individuals to take part. So, I very much hope that you or one of your colleagues will be able to spare the time to speak to a researcher from SPRU. Everything that is said to the researchers will be treated in strict confidence. Their report will not identify individuals or practices and details of these will not be passed to anyone outside of the research team.

You will find enclosed a letter from SPRU setting out how they would like your practice to participate in the research and a summary sheet explaining the full range of work they are carrying out for DWP.

If you would like to know more about this research, please call me, Jo Bacon, on 020 7962 8003 or either of the two principal researchers at SPRU, Dr Roy Sainsbury and Anne Corden, on 01904 433608. We will be happy to answer any queries you may have.

Yours sincerely

Jo Bacon  
Senior Research Officer  
Department for Work and Pensions



RS/RD

Title

Address

Email: rds2@york.ac.uk

Date

Dear

**Evaluation of Medical Evidence Gathering for Incapacity Benefit pilot**

As explained in the letter from Jo Bacon, the Department for Work and Pensions has commissioned the Social Policy Research Unit at the University of York to conduct research on the pilot project on Medical Evidence Gathering for Incapacity Benefit.

It is important that we seek the views of this way of supplying evidence among General Practitioners not only from those who have been participating in the pilot but also from those who have decided not to participate. One of the research team will be telephoning you shortly, and we hope that you will agree to meet and take part in a research interview, at a time and place convenient to you.

Topics for discussion in the interview include:

- your reasons for declining to take part in the evidence gathering pilot
- your experiences of existing processes
- your views about using patients' case notes in this way
- your suggestions for improving medical evidence gathering arrangements more widely.

The discussion will take about 45 minutes to one hour, and we are able to offer an honorarium of £75. Everything discussed will, of course, be dealt with in confidence.

We thought it would be helpful to enclose here a summary of the overall research design.

We hope that you will be interested in taking part in this research and will be able to offer us an appointment.

Yours sincerely

Dr Roy Sainsbury

### **Information about research on the Medical Evidence Gathering pilot**

#### *The Medical Evidence Gathering pilot*

The aim of the pilot is to test alternative arrangements designed to provide Jobcentre Plus Decision Makers and Medical Services doctors with better evidence on which to base decisions about eligibility for Incapacity Benefit and to reduce benefit related paperwork for GPs.

The pilot has been running in the Sheffield/Rotherham area since January 2002. People applying for Incapacity Benefit who agree to take part, and whose GPs have also agreed to take part, are assessed for eligibility on the basis of evidence taken directly from medical case notes.

#### *What is the Social Policy Research Unit?*

The Social Policy Research Unit is an independent research unit within the University of York. It is known for high quality research to inform social policy in areas including health and social care, family policy, employment, and disability. Funding comes from a variety of sources, including major government departments.

The research team for this qualitative enquiry into the Medical Evidence Gathering pilot are Dr Roy Sainsbury, Anne Corden, Professor Peter Kemp, and Hanif Ismail, who between them have considerably experience in evaluative research on the administration and delivery of services and benefits.

### **Qualitative Research on the Medical Evidence Gathering pilot**

The aim of SPRU's research is to evaluate the pilot in relation to:

- the impact on GPs
- quality of medical evidence given to Benefits Agency Decision Makers
- the impact on decision-making
- the overall effectiveness of the new procedures.

SPRU will seek views and experiences of the pilot among the key groups of people:

- GPs taking part in the pilot
- GPs choosing not to take part in the pilot
- GP practice staff involved at a procedural level
- applicants for Incapacity Benefit who are taking part in the pilot
- applicants for Incapacity Benefit choosing not to take part
- Benefits Agency processing staff and Decision Makers
- Medical Services doctors.

Information will be sought in personal interviews and group discussions, and dealt with in confidence. A draft report of the findings will be passed to the Department for Work and Pensions in early 2003, and a final report agreed by March 2003. Results will be published, and made available in summary form to people who contributed to the research.

Further information about the pilot is available from Jo Bacon at the Department for Work and Pensions on 020 7962 8003.

**DWP** Department for  
Work and Pensions

Name and Address

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Date

19 June 2002

Reference

Dear

### Benefits and medical records

I am writing to ask for your help with some important research that is being carried out among people who have recently made a new claim for incapacity benefit or whose claim is being reassessed. The Department for Work and Pensions is testing a new way of collecting medical information for benefit claims by using GP medical records, and we would like to find out what people think about it. The research is being carried out on behalf of the Department by an independent research organisation, the Social Policy Research Unit at the University of York.

A researcher from the Social Policy Research Unit may contact you soon to see whether you are willing to be interviewed as part of the study, and if so to arrange a time to meet with you. The interview would last about an hour. Anything you say to the researcher will be strictly confidential; your name and personal details will not be passed to any government department or anyone else. *Everyone who is interviewed will be given £15 as a small token of thanks for their help. Taking part in this study will not affect any benefit you receive, or any dealings you may have with any government department or agency.*

When the researcher gets in touch they will tell you more about the research and answer any questions you might have. Please let us know if there is anything we can do to make it easier for you to take part. The researcher who contacts you will also be glad to talk about any requirements you may have or arrangements that would be helpful.

I do hope you decide to take part in the study – the value of the research depends on people's willingness to help. If, however, you do not wish to take part, please let us know by Thursday 4 July quoting the reference number at the top of this letter. You can either write to us at the FREEPOST address above, or telephone the research team secretary, Sally Pulleyn on 01904 432626. If you would like to know more about the research, you can also call me, Jo Bacon, on 0207 962 8003.

Thank you for your help. I hope you will be able to take part in this important study and enjoy talking to the researcher.

Yours sincerely

Jo Bacon  
Senior Research Officer



# Appendix D

## Administrative context of Incapacity Benefit decision making

### D.1 Incapacity benefits

State incapacity benefits provide a replacement income to people below state pension age who have to stop working or looking for work as a result of sickness or disability.

People gain entitlement to one of the incapacity benefits depending on whether they have:

- (a) paid enough National Insurance contributions on their earnings, and
- (b) satisfied the relevant medical test.

#### D.1.1 National Insurance Contributions

If a person has paid or been credited with a minimum level of National Insurance contributions (NICs) and they satisfy the relevant medical test (see below) they will be entitled to contributory *Incapacity Benefit (IB)*.

If a person has not paid enough NICs but satisfies the relevant medical test, he or she can get National Insurance Credits. If they have a low income, then they can claim *Income Support (IS)* on the grounds of incapacity. People may also be able to get IS to top-up their IB where they have no other income.

If a person has not paid enough NICs, but has been treated as incapable of work for at least 196 days and that period of time began before the age of 20 (25 for those in education or training before age 20) he or she is now able to claim IB. Before April 2001 they would have claimed *Severe Disablement Allowance (SDA)* as would others who satisfy the 196 day test and were classified as 80 per cent disabled. SDA was abolished from April 2001 for new cases but existing recipients continue to receive it.



### D.1.2 Relevant medical test

There are two different tests of incapacity that apply in different circumstances the *Own Occupation Test* and the *Personal Capability Assessment*.

People who have been working recently need to satisfy the *Own Occupation Test*. This is a test that looks at whether ill-health or disability stops a person from doing their *normal* job (with adjustments where necessary). A certificate from a medical practitioner, usually the person's GP, is normally sufficient to satisfy this test.

Employees need to satisfy an own occupation test to get Statutory Sick Pay (SSP). SSP is paid for up to 28 weeks. However some people who have been in employment are able to claim IB straightaway because they cannot get SSP. This group is made up of the self-employed, employed earners getting less than £75 per week, and people who have only recently become unemployed or whose contracts ended while they were sick. This group needs to satisfy the own occupation test for their first 28 weeks on benefit.

After 28 weeks on an incapacity benefit the groups affected by the Own Occupation Test are required to satisfy a different test, the *Personal Capability Assessment (PCA)*. All other clients are required to satisfy the PCA from the outset of their claim. This includes those who have been unemployed or otherwise out of work and those moving across after 28 weeks on SSP.

The PCA (previously known as the 'All Work Test') is the medical test that is used to decide entitlement to longer-term state incapacity benefits. In contrast to the Own Occupation Test, it looks beyond ability to perform the normal occupation to look at the extent to which a person's condition affects their ability to do a range of everyday work-related activities covering:

- physical functions such as walking, bending and kneeling, sitting in a chair;
- sensory functions such as ability to speak, hear or see; and
- mental functions such as interacting with others and coping with pressure.

Approved doctors working for Medical Services on behalf of DWP assess the extent to which a person's health condition impairs their ability to perform any of these key activities. They then provide advice to a benefit *decision maker*. A person satisfies the PCA if their ability to perform any *individual* activity is seriously curtailed (for example they cannot walk more than 50 metres without stopping, or they cannot turn the pages of a book). Alternatively the PCA can be satisfied if there is a lesser degree of impairment *across a number of activities* (for example a person cannot stand up without holding onto something and cannot see well enough to recognise someone at 15 metres). It can also take account of the combined effect of mental and physical health problems.

Importantly, the PCA is not a test that distinguishes between people who can and cannot work. Rather it draws a line between people who should not be expected to seek work in return for benefit (those satisfying the PCA who stay on IB) and those who can be expected to do so (who can attempt to move back to work or claim JSA).

Around 20-25 per cent of people on IB have very severe medical problems and are exempt from the PCA process. This group includes, for example, those who are already in receipt of highest rate care component of Disability Living Allowance, those with terminal illnesses and those with severe conditions like tetraplegia, chronic degenerative disease and schizophrenia.

The PCA process requires the collection of evidence to inform the advice which the approved doctor provides to the decision maker and will involve some or all of:

- a request for information from the doctor issuing sickness certificates;
- in most cases, the completion of a detailed questionnaire by the customer about the impact of their condition on the work-related activities;
- consideration of the paper evidence by an approved doctor to advise whether the customer's self-assessment is supported by the medical evidence (paper scrutiny);
- in about a third of cases, where further evidence is required, a face-to-face medical examination with an approved doctor.

Approved doctors provide medical advice in relation to the PCA to a Jobcentre Plus decision maker who makes the decision on benefit entitlement. Because of the need to collect sufficient evidence, the entire PCA process can take some time to complete. In the meantime, incapacity benefits can be put into payment supported by evidence from the patient's own doctor.

Where a person does satisfy the test, a date will be set on medical advice for a further PCA to identify whether a person's condition has improved. Usually this is at an interval of between 3 and 18 months, depending when a change might be expected. Even where significant change is unlikely, cases are checked periodically. Procedures were standardised in May 2001 so that all cases going through the PCA are scheduled for consideration of a further test at least after 3 or 5 years (except for a small number of people with severe conditions where this would clearly be inappropriate).



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# Acknowledgements

Thanks are due to all those people who took part in the research, and spent time talking to us about their views and experiences. Included here are the people who had claimed incapacity benefit; GPs and practice staff; staff in Jobcentre Plus; staff in the Leeds Medical Services Centre and doctors working in the Sheffield Medical Examination Centre.

Jo Bacon managed this project for the Department for Work and Pensions, and we are grateful for her help throughout. We also thank members of policy branches of the Department for Work and Pensions and project staff of SchlumbergerSema for their help and interest.

The team of researchers, which undertook the fieldwork, included Peter Kemp and Hanif Ismail. The administrative support for the project from Sally Pulleyn, Teresa Frank, Sarah Starkey and Julie Williams was essential. Thanks go particularly to Sally Pulleyn who had major responsibilities in supporting the fieldwork and who prepared the manuscript.

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# Summary

## Chapter 1: Introduction

The background to this research was policy concern with current arrangements for collecting medical information from certifying medical practitioners for use in determining entitlement to state incapacity benefits. Inadequate and low quality information collected from some certifying medical practitioners can lead to inefficiencies in the system resulting in unnecessary demands on sick and disabled people; procedural inconsistencies and frustrations, and inappropriate and wasteful use of DWP, Medical Services and Appeal Service resources. In addition, current arrangements create an unwelcome burden of work for some certifying medical practitioners, most of whom are GPs (Section 1.1).

The Better Medical Evidence Gathering pilot was undertaken in Sheffield and Rotherham in 2002, as one of a number of initiatives designed to improve advice and decision making for incapacity benefit. The aim of the research reported here was to evaluate this pilot (Section 1.2). A qualitative approach was appropriate, seeking views and experiences from the main actors: claimants, GPs and practice staff, processing staff and decision makers in Jobcentre Plus and Medical Services, and approved doctors (Section 1.3).

Determination of entitlement to incapacity benefit is a complex process involving collection of information from the claimant and their GP, consideration of this documentation by approved doctors, medical examinations for some claimants, and decision making by Jobcentre Plus staff. The essential difference between current arrangements and those in the pilot was that rather than asking GPs to provide information to the approved doctor (medical officer) on the standard report forms, medical information was extracted directly from claimants' GP record. Both the GP and the client themselves needed to consent to this new arrangement (Section 1.4).

## Chapter 2: Views and experiences of GPs and practice staff

Views and experiences were sought from GPs and administrative staff in 29 practices in the pilot area, of which 17 had agreed to take part in the pilot and 12 had declined.

It appeared that the views of the practice manager could be highly influential in initial decisions about whether to take part in the pilot. The main attractions had been the saving in GPs' time and reduction of form filling, and provision of a more balanced picture for benefits decisions. GPs who remembered declining to take part had concerns about patient consent and confidentiality. Some saw potential risk of loss of or damage to records, or records being away when needed (Section 2.1).

There was mixed evidence of any impact of the pilot on GPs themselves. Reduction in workload had been noticed mainly by GPs who usually dealt with higher numbers of IB113 report forms or spent some time completing each form. GPs reported no negative impacts for themselves or patients. In terms of administrative work required, the process was quickest and easiest for practices sending actual GP records. Practices sending photocopied records found this time consuming, and considered the additional honorarium insufficient. The arrangements for collection and return of records generally worked well (Section 2.2).

GPs had differing views on completing IB113 forms for patients claiming incapacity benefits, which influenced their overall feelings about the pilot arrangements. GP records were generally felt to provide fuller information, which could lead to better benefits decisions and save GPs some time. There remained some concerns about patient consent to release of full records, patient confidentiality, and the low quality of some records. Initial concerns about the practicalities of transferring the information decreased during the interview, as understanding grew (Section 2.3).

## Chapter 3: Views and experiences of incapacity benefits claimants

The claimant study group included 22 claimants who were pilot participants and ten non-participants.

Not everybody in this group was aware of their relationship to the pilot, and some initially recalled little about it. Those who remembered making a decision about taking part had known that participation was voluntary (Section 3.1).

People did not need full understanding of details of the pilot in order to agree to take part. Reasons for taking part fell into two groups: possible direct consequences for themselves and other claimants, and perceptions of the new arrangements as a generally better way of doing things. For example, some people hoped that by taking part they would avoid a medical examination, while some believed generally that advances in society required readiness to try new things. Just feeling that they had nothing to hide could be sufficient. Reasons for not taking part were remembered by only a small group of people. Mentioned here were issues of confidentiality and other concerns about possible negative outcomes for themselves (Section 3.2).

Not everybody was interested in what actually happened during medical assessment for incapacity benefits, but most thought that DWP would look at what they themselves had written on the standard forms and seek some medical information as proof of entitlement. People generally suggested their GP as one source of such information; other suggestions included hospital and clinic staff, and employers. There was a general perception that everybody receiving incapacity benefit would eventually be asked to have a medical examination. Long-term incapacity benefits claimants had the best grasp on the overall procedures (Section 3.3).

Claimants' views on the pilot arrangements were likely to depend partly on their relationship with their GP. There was wide variation here. Similarly, there was variable knowledge about what was contained in GP records. There was general acceptance of the importance of medical examinations in assessment for incapacity benefit, even among people with previous bad experiences (Section 3.4).

Towards the end of the research interview, when some claimants were better informed about the pilot, people weighed up advantages perceived against potential negative effects. There were a number of arguments on both sides (Section 3.5).

Most of those who had taken part in the pilot were content to have been included, although some wished they had understood more at the time. Most people recruited as non-participants appeared more positive about the new arrangements by the end of the discussion. People were interested in the pilot as a way of testing a new idea. Most felt it would be all right to introduce the new arrangements nationally, although some felt other claimants and some GPs would not like this, and some were puzzled as to how consent would be dealt with. People stressed the importance of maintaining confidentiality, and careful handling and speedy return of GP records. The small number of people who disagreed with the new arrangements had strong negative views (Section 3.6).

## Chapter 4: Administering the pilot arrangements

Group discussions with three teams of Jobcentre Plus administrative staff were conducted at the end of the implementation of the pilot. The main impacts reported by processing staff were an increase in the number of administrative decisions required, and more clerical and manual work in dealing with claims. One contributory factor was that no new computer programmes were inserted for managing the pilot. Other factors included complexities arising from apparent changes in status of individual claimants between 'participant' and 'non-participant' while their claim was dealt with. Some changes in staff instructions in the early part of the pilot also required new learning. Looking back, staff would have liked more IT support, and more overall support and information during the pilot.

The pilot increased the number of telephone enquiries from claimants, but there were few calls from advisers or health/care professionals.

On balance, it was thought better to have run the pilot than not, when considering a major change in procedure. The processing staff involved in the pilot now have key information and expertise on which to draw if decisions are taken to develop or extend the new arrangements (Section 4.1).

At the Leeds Medical Services Centre the team leader who oversaw administrative work reported that the pilot required a number of new procedures and additional work. This was not in itself problematic. Should the pilot be extended, attention is required to the resource implications for collection of GP records and their secure handling and storage. Different kinds of consent procedures would make administration easier (Section 4.2).

## Chapter 5: Using GP records in the administration of incapacity benefit

Approved doctors provide Decision Makers with advice about whether a claimant should be exempt from the Personal Capability Assessment (PCA) and about whether a client undergoing the PCA requires an examination. Their additional task under the pilot arrangements was to extract data from GP records and prepare a new report (form SB2) which summarised the relevant evidence from the GP notes. All of the approved doctors who prepared the SB2 reports were interviewed.

Advising whether a claimant's condition was likely to meet the legal requirements for exemption from the PCA was reported to be generally relatively straightforward. The GP records were thought to contain more information than most IB113 forms, and often allowed doctors to form a view about the severity of the condition, which could be helpful. Fuller information led to an increased level of confidence. There was a preference for using GP records to make decisions about exemption, although the process was thought to take slightly longer. The impact on the substance of decisions made was thought to be marginal (Section 5.1).

The process of extracting data from GP records, under the pilot arrangements, was defined under administrative rules. Extracts relevant to the claim were copied directly from the GP records, and additional notes made by the approved doctor drawing attention to any relevant gaps, or highlighting specific issues for the benefit of the subsequent examining doctor.

Two different approaches to extraction of data emerged, with respect to what kind of data was thought relevant, and the amount of, and type of, information extracted had sometimes changed over the course of the pilot. Points made consistently were that GP records varied considerably in quality (content and legibility) and were not geared towards assessing a patient's functionality.

Gaps in the claimant's medical history were not usually followed up with the GP, nor were GPs asked for further information if their records were illegible (Section 5.2).

The view of the approved doctors was that the proportion of PCA cases scrutinised where the advice was to call the claimant for medical examination had probably increased under the pilot arrangements. Contributory factors included having more relevant and up-to-date information, more extensive information, and more accurate information (Section 5.3).

Overall, there was preference for providing advice to Decision Makers based on GP records. These were available in all pilot cases. GP records varied in quality but compared favourably with quality of information on IB113 forms and Med4s, and often provided more accurate, more objective and more up-to-date clinical information. Disadvantages were that GP records contained little direct information about functionality. One criticism of the pilot was that the administrative rules were too rigid with respect to the time span of the information to be extracted (Section 5.4).

## Chapter 6: Using extracts from GP records in the administration of incapacity benefit

Approved doctors who provide advice to Decision Makers on the paper evidence and approved doctors who provide advice following an examination, were the principal users of the information extracted from the GP records (i.e. the information on the SB2 form). This information was also made available to decision makers in Jobcentre Plus who are responsible for making the decisions on benefit entitlement. The researchers interviewed all six approved doctors conducting regular medical examinations of claimants under pilot arrangements. Views were sought from all ten decision makers in Sheffield and Rotherham in six individual interviews and one group discussion.

The role of the incapacity benefits approved doctor, acting as an Examining Medical Officer (EMO) is to conduct medical examinations with incapacity benefits claimants and write medical reports for use by decision makers. In preparing for the examination, EMOs have access to all relevant documentation held by DWP relating to the claimant. They use this to identify aspects of medical history or functionality for exploration in the medical examination. EMOs did not mention to claimants in the pilot that they had access to extracts from their GP records, to avoid damaging relationships between patients and GPs (Section 6.1).

EMOs said they had been surprised that the pilot arrangements had little impact on the process of examining claimants or their choice of descriptors of functionality in their reports. Possible explanations included a usual lack of information about functionality in the extracts from GP records. In comparison, they could collect themselves a substantial amount of relevant information during an examination. However, some EMOs liked having fuller medical histories from GP records, and for some claimants fuller information meant EMOs could set a longer re-referral date.

All EMOs spent more time on their reports under the pilot arrangements. Some felt their advice about descriptors was better justified; none experienced an adverse effect (Section 6.2).

EMOs compared using extracted information on SB2 forms with information supplied by GPs on IB1 13 forms, under pilot and usual arrangements, respectively. Although most felt IB1 13 forms had greater potential for generating information about functionality, in practice many such forms contained little or none. Some EMOs felt the SB2 forms contributed to greater objectivity. There were mixed views about whether it was necessary to consider information from the last five years of GPs' records. EMOs agreed that neither the pilot nor the usual arrangements were designed to generate information directly from other health professionals, but there were differing views as to whether this omission was important. The IB1 13 forms could be easier to understand if the GP gave a coherent summary of the claimant's health. Piecing together a medical history from chronological extracts on the SB2 could take longer. Legibility of GPs' records remained an issue under both arrangements (Section 6.3).

There was no consensus of preferences for the pilot or usual arrangements. Preferences for the pilot arrangements were based on the guarantee of at least some information from the GP, a more complete clinical picture, and more objective information. Disadvantages included an additional time requirement (reading and writing reports) and lack of direct information about functionality. The main advantage of working with the IB1 13 forms was that questions were designed to elicit relevant information about functionality (Section 6.4).

Most of the Jobcentre Plus decision makers' work is concerned with claimants where the medical evidence indicates that they have not met the PCA eligibility criteria, usually following a PCA medical examination. Decisions are usually hardest to make when claimants score themselves above the threshold but the advice from the EMO indicates that they score below the threshold. What decision makers require here is good quality information. Any factual information from the claimant's own doctor, usually the GP, is considered alongside the claimant's choice of PCA descriptors and the EMO's evidence and advice (Section 6.5).

Decision makers had been surprised and disappointed that the pilot arrangements had little impact on the quality of medical reports produced by EMOs, or the substance and quality of their own decisions. Certainly, medical reports written for pilot cases generally included justification for choice of descriptors, but what was written was not always useful. Some decision makers were definite in their view that their decisions would have been exactly the same under usual arrangements. Those who had seen fewer cases found it hard to make an assessment here. There was no feeling that the pilot arrangements had increased confidence in decisions (Section 6.6).

Decision makers reflected on experience of using SB2 forms in comparison with IB1 13 forms and Med4s. In terms of usefulness, a common perception was that much clinical data contained in the SB2 was hard for them to understand and interpret, especially if there were technical terms or diagrams in GP records. They felt unable to use much of what was in the SB2 forms. IB1 13 forms, well completed by GPs, were generally better at providing information about functionality, but failure to return IB1 13 forms and paucity of information in some was a problem. Legibility of handwriting was a source of continuing concern and frustration, and decision makers were surprised that approved doctors were not transcribing more of the information on the SB2. Extracts on SB2 forms ending in mid-sentence could raise doubts about missing information, and reduce confidence in decisions (Section 6.7).

Decision makers expressed no strong views about preferences for working with the pilot or usual arrangements, and there was no consensus. Some felt the principle of the IB1 13 was superior, but in



practice produced variable information and sometimes none. Some felt it was better to have at least some information from GPs for all decisions (Section 6.8).

## Chapter 7: Developing policy for the collection of medical evidence

A number of policy issues emerge from this study which will need consideration in any reforms to incapacity benefit procedures.

One issue is the acceptability of using GP records. It is possible to design systems for collection and return of GP records which would address objections in terms of the practicalities for GPs and claimants. Objections in principle on grounds of confidentiality are likely to remain for some.

More robust methods of increasing claimants' understanding and seeking their consent should be explored, and could help to persuade more GPs that their patients have given fully informed consent.

The amount of additional administrative work created for practice staff was variable, and raises issues about any additional remuneration. Thinking about future arrangements will need to take account of the diversity in, and possibilities of the use of, information technology. Practice managers played key roles during the pilot and their views will be particularly important.

Overall, GP records are useful in providing evidence of diagnosis of health conditions, but less useful for judging functionality. The IB113 form can be useful on both counts if filled in well, but this does not happen sufficiently often. It is hard to prescribe with any certainty but, for new claimants, an extract from the GP records covering the last 12 to 24 months may be satisfactory. There was no consensus among the professionals about the value of information collected from additional sources, although claimants felt this could be important.

Further work is necessary to evaluate what impact there might be on the appeals system from the pilot arrangements (Section 7.1).

The research has provided some lessons about running a pilot which could be useful in future evaluations (Section 7.2).

The study had provided suggestions for improving the collection of medical information in the future. In terms of revision of the current IB113 form, flow and quality might be improved by introducing different systems for remunerating GPs; taking more proactive management action for non-compliance with GPs' terms of service; quality control procedures and enhanced GP training. In terms of building on the pilot arrangements, suggestions were aimed at increasing operational effectiveness and efficiency. Other ideas included different combinations of administrative process (Section 7.3).

The report ends by returning to the research aims (Section 7.4). The pilot has had mixed results. The effect at the level of the individual GP was only noticed in particular practices. Among the users of medical information, approved doctors preparing the SB2 report (case note extract) and providing advice to decision makers on paper evidence were closest to the raw material of the GP records and found them the most useful. There was no consensus among the EMOs about which arrangements were preferable. For decision makers information on SB2 forms was generally of less use than information on the usual IB113 forms.

# 1 Introduction

This report presents findings from qualitative research to evaluate the Better Medical Evidence Gathering Pilot undertaken for the Department for Work and Pensions (DWP) in the Sheffield and Rotherham area during 2002. The aim of the pilot was to test alternative arrangements for providing medical evidence to approved doctors<sup>1</sup> who give advice to decision makers who determine eligibility for state incapacity benefits. These new arrangements would, it was hoped, improve the evidence gathering process for incapacity benefit, and the overall efficiency of the decision making process. The study was conducted by the Social Policy Research Unit (SPRU) at the University of York for DWP, and took place concurrently with the pilot during 2002.

## 1.1 Background and research

### 1.1.1 The policy context

During the past 12 to 15 years there has been considerable policy interest in long-term sickness benefits. This was prompted initially by a growth in the numbers of recipients<sup>2</sup>. The reasons for the increase are not straightforward, but it is thought that economic trends, demographic changes and benefit administration have all contributed to the rise (Department for Work and Pensions, 2002a). Benefit administration has also attracted the interest of the Social Security Select Committee (2000) and the National Audit Office (2001), who have identified problems with the current arrangements for incapacity benefits.

### 1.1.2 Concerns about the current arrangements

Incapacity benefit<sup>3</sup> is the main state benefit for people whose health or disability is deemed such that it is not reasonable to expect them to seek work as a condition of receiving benefit. People gain entitlement to incapacity benefit if they have National Insurance contributions on their earnings and

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<sup>1</sup> See Note on Terminology in Section 1.6 of this chapter for an explanation of the term 'approved doctor'.

<sup>2</sup> In 1979, 690,000 people received Invalidity Benefit and Invalidity Pension (the forerunners to the current incapacity benefits). By February 2002 the number on Incapacity Benefit had risen to 2.3 million.

<sup>3</sup> Incapacity Benefit is a generic term covering contributory Incapacity Benefit and Income Support (on the grounds of incapacity). Both provide a replacement income to people below state pension age who have to stop working or looking for work as a result of sickness or disability. If someone has low income, they can claim Income Support on the grounds of incapacity and may also be able to get income support to top-up their Incapacity Benefit where they have no other income.

they satisfy the relevant test of incapacity<sup>4</sup>. The incapacity benefit decision-making process relies on a questionnaire completed by the claimant, medical advice from an approved doctor (which may include evidence collected in a face-to-face examination) and factual evidence from the claimant's own doctor, usually the GP. Concerns with the process have included the adequacy and quality of the factual medical evidence collected from GPs. Staff involved in the advisory process sometimes feel that this evidence does not enable them to give confident and accurate advice and that subsequent decision making may be affected. As a result it is likely that:

- some claimants, who should be exempt from supplying additional information about themselves because of the severity of their condition, are not identified at an early stage in the assessment process and may be called inappropriately for a medical examination;
- some claimants who should be assessed on paper evidence as meeting the eligibility criteria are not identified and are called for an unnecessary medical examination;
- some claimants may be wrongly awarded incapacity benefit on the basis of inadequate medical evidence; and
- some disallowed claims are eventually overturned at an appeal tribunal when benefit should have been allowed earlier.

Such inefficiencies in the system are thought to result in unnecessary demands and additional stress on people who are sick or disabled; inconsistencies in procedure and decision making at the operational level; frustration for Jobcentre Plus staff who administer incapacity benefit and approved doctors who provide them with medical advice; and inappropriate and wasteful use of Medical Services resources. Other evidence suggests that the decision-making process could be improved. For example, there is a high level of success for claimants who appeal against disallowance - for the quarter ended March 2002, of those claimants who appealed against disallowance of benefit following a 'Personal Capability Assessment' (see Section 1.4) over 40 per cent had the decision overturned (Department for Work and Pensions, 2002b).

An additional concern is the amount of work created for GPs under current arrangements for determining eligibility for incapacity benefits (Cabinet Office, 2001, 2002). Recent research (Hiscock and Ritchie, 2001) has shown that completion of the required forms and reports represents an unwelcome burden of additional work to many GPs. Such factors may all affect the quality and consistency of medical evidence provided by GPs under the current system. Indeed, internal reports coming from the new Appeals Service refer, among other things, to the unsatisfactory quality of medical evidence produced by GPs.

The problems and concerns identified above have led DWP to examine the medical evidence gathering process for incapacity benefit and to consider ways of improving quality and efficiency. This has led to the introduction of a series of pilots with this aim. These are:

- The Better Medical Evidence Gathering Project. This is a DWP initiative undertaken in the Sheffield and Rotherham area during 2002 and the subject of this research study. The aim of the pilot was to test alternative arrangements for obtaining medical evidence from the claimant's own doctor.
- Evidence Based Medicine project. This is a joint Medical Services/DWP initiative to develop a computerised process to support the provision of advice following a medical examination.

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<sup>4</sup> If a person has not paid enough National Insurance contributions but satisfies the relevant medical test, he or she can get National Insurance credits.

- IB113 project. This project is also concerned with gathering factual evidence from the claimant's own doctor. It involves piloting a new version of the medical report form sent to GPs.

## 1.2 Research aims and objectives

This research was concerned with the Better Medical Evidence Gathering pilot. In order to inform future policy decisions, there was a need for information about the impact of the pilot. Policy makers sought information about the way in which the pilot was put into operation. They sought greater understanding of the way in which claimants, GPs, approved doctors and decision makers perceived and experienced the pilot arrangements and, specifically, the use of GP case records in making more informed decisions. More detailed information is intended to help policy makers achieve the most appropriate arrangements for providing medical evidence for incapacity benefit claims.

The aim of the research was to evaluate the Evidence Gathering pilot in relation to:

- issues for incapacity benefit claimants;
- the impact on GPs;
- the quality of medical advice given to decision makers;
- the impact on decision making; and
- the overall effectiveness of the new procedures.

Research objectives were:

- to explore whether the pilot arrangements promote appropriate high quality medical advice following scrutiny of documentation which would reduce the need for the claimant to undergo a medical examination;
- to explore whether the pilot makes available better quality medical information to doctors carrying out medical examinations, increasing their ability to give high quality advice to decision makers;
- to explore whether the pilot produced better evidence to help decision makers to make confident decisions;
- to explore understanding of the new arrangements and influences on participation among claimants and GPs; and
- to explore whether GPs, approved doctors and Jobcentre Plus staff find the process of gathering information from case notes workable and appropriate, and suits the needs and circumstances of claimants.

## 1.3 Research design and methods

A qualitative approach was appropriate for evaluating the Evidence Gathering pilot, its impact on GPs, approved doctors, decision makers and claimants, and their perception, views and experiences<sup>5</sup>.

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<sup>5</sup> The qualitative research complements the in-house analysis of administrative data designed to look at the characteristics of various groups of participating and non-participating claimants, and assess the impact of the pilot on incapacity benefit allowances and disallowances and the flows of claimants through various stages of the claiming and decision making process.

The researchers made initial site visits to the Sheffield Jobcentre Plus office, and the Leeds Medical Services Centre, for early discussion with staff about implementation of the pilot arrangements and issues arising.

In depth interviews were carried out with:

- new claimants participating in the pilot;
- new claimants not participating in the pilot;
- re-referral claimants participating in the pilot;
- re-referral claimants not participating in the pilot;
- GPs participating in the pilot<sup>6</sup>;
- GPs not participating in the pilot<sup>7</sup>;
- administrative staff in participating GP practices;
- approved doctors in the Leeds Medical Services Centre;
- approved EMOs operating in Sheffield and Rotherham;
- Medical Services operational manager for the pilot;
- Jobcentre Plus decision makers.

Group discussions were carried out with:

- Jobcentre Plus decision makers;
- Jobcentre Plus incapacity benefits processing staff.

The interviews and group discussions were undertaken in the Sheffield and Rotherham areas, the location chosen by the Department for Work and Pensions for this pilot<sup>8</sup> and at the Leeds Medical Services Centre. Appendices A-C contain details of the research methodology, including sampling and recruitment, research instruments used in interviews, and letters of invitation to take part in the study sent to GPs and to incapacity benefit claimants.

## 1.4 Administrative context

### 1.4.1 Current arrangements for the decision-making process for Incapacity Benefit

For those in employment, an incapacity benefit claim is usually only possible after they have satisfied the Own Occupation Test to get Statutory Sick Pay, which is paid for up to 28 weeks.<sup>8</sup> After 28 weeks, they are required to satisfy a Personal Capability Assessment (PCA), which is the medical test used to decide entitlement to incapacity benefit. All other claimants are required to satisfy the PCA from the beginning of their claim. The PCA provides an indication of the extent to which a person's condition

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<sup>6</sup> In four cases, practices managers were interviewed instead of GPs.

<sup>7</sup> One advantage of choosing this area was that some claimants' and GPs' experiences would have had experience of the Miners Compensation Scheme which uses a similar method of collecting information.

<sup>8</sup> This looks at whether ill health or disability stops a person from doing their normal job. A certificate (Med 3) from a medical practitioner, usually the person's GP is normally sufficient to satisfy the test.

affects their ability to do a range of everyday work-related activities covering:

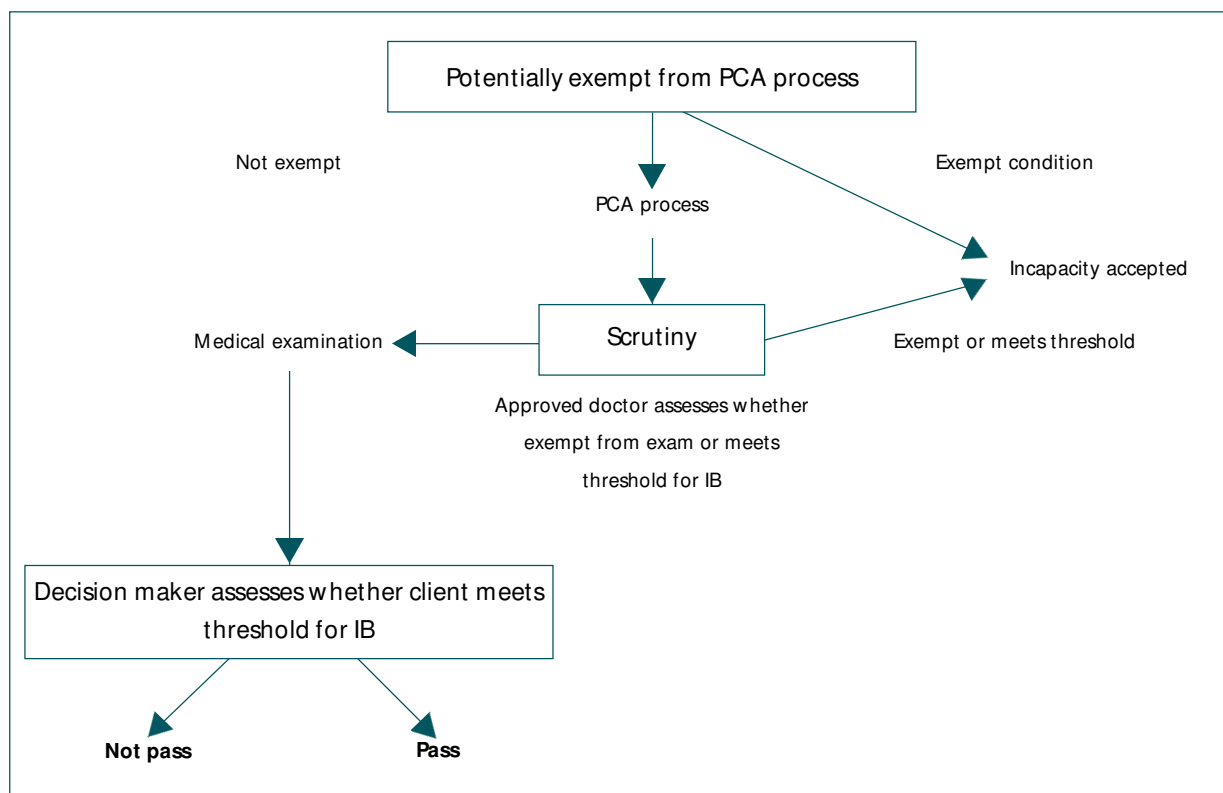
- physical functions such as walking;
- sensory functions such as ability to hear;
- mental functions such as interaction with others.

The PCA requires the collection of paper evidence to inform the decision-making process. This process is outlined in Figure 1.1 and detailed in the text below. A person may qualify for incapacity benefit on the basis of meeting the threshold for functional limitation in any one of the mental, physical or sensory activities, or on the basis of a combination of less severe limitation across several areas of function.

Following a claim to state incapacity benefit, before the PCA is first applied, benefit is paid if supported by evidence from the claimant's own GP. When the PCA is applied, those people who do not meet the threshold for incapacity are disallowed further incapacity benefit, have their award terminated, and are expected to seek work as a condition of receiving further benefit. For those people who do meet the threshold for incapacity, a date will be set for a further PCA to identify any change in a person's condition.

Appendix D provides a fuller explanation of the purpose of the PCA and the administrative procedures involved.

**Figure 1.1 The Incapacity Benefit decision-making process**



## 1.4.2 The Incapacity Benefit decision-making process

### Potential exemption from the PCA process

The first stage of the decision-making process is to establish whether the claimant is exempt from the PCA process. This stage is necessary in about a third of cases where there is some evidence to suggest that the claimant might fall into an exempt category. In many cases the decision maker will seek medical advice on this matter from an approved doctor. The approved doctor will seek factual information from the certifying medical practitioner (usually the claimant's own GP) on form IB113. Those with very severe medical problems are awarded incapacity benefit without having to go through the PCA process. In certain cases, Jobcentre Plus processing staff can make a decision whether to exempt the claimant from the process. These include claimants with a terminal illness, those in receipt of the highest rate care component of Disability Living Allowance and those with severe conditions like paraplegia, dementia and registered blindness. In other cases, such as mental illness, progressive impairment of cardio-respiratory function, or dense paralysis, the decision to exempt the claimant from the PCA process is undertaken following advice from an approved doctor.

Claimants who are not exempt are asked to complete a detailed questionnaire (form IB50) about the impact of their condition on a range of work-related activities as defined in the PCA. This asks the claimant to select from a number of options the statement that best explains any functional limitation they may have in each physical and sensory area listed. In the technical language of the decision-making process, this is referred to as making a choice of 'descriptors'. Each descriptor has an associated 'score' that is designed to represent the degree to which it affects activities of everyday life. If the claimant scores 15 points in any one activity, or a total of 15 points from a combination of activities, the threshold of incapacity is met for benefit entitlement purposes. A separate system of scoring applies to activities that are affected by the presence of mental health conditions (see section 1.4.3 below). Claimants are encouraged to provide any additional information that may assist the decision process or affect their ability to perform work-related activities. The incapacity benefit claimant returns the questionnaire (form IB50) to the Jobcentre Plus office along with a Med 4 statement from their own doctor, if the approved doctor has not already requested an IB113 report.

### Scrutiny

At the next stage of the PCA process, an approved doctor, working on behalf of the Department for Work and Pensions, considers whether the claimant's self-assessment (IB50) is supported by medical evidence that may be available from the IB113 or Med 4 (referred to as paper scrutiny). When a claimant's IB 50 scores above the PCA threshold, and this is supported by the available medical evidence the approved doctor will advise the decision maker to accept the score. Thus the claimant satisfies the PCA eligibility criteria for incapacity benefit (these are referred to as cases which 'pass on scrutiny'). Where there is a lack of available information or an apparent contradiction between the claimant's IB50 and the available medical evidence, the approved doctor will call for further evidence. This will usually be in the form of a medical examination of the claimant where an approved doctor (known as an Examining Medical Officer, or EMO) carries out a face-to-face medical examination with the claimant. The examining doctor will make an assessment of the level of functional ability in each of the activity areas and the presence of any non-functional restrictions. He/she will then prepare a detailed incapacity report for the decision maker (form IB85).

### Decision maker assessment of whether claimant meets threshold for incapacity benefit

Approved doctors then pass all the medical evidence in relation to the PCA to the Jobcentre Plus decision maker, who makes the decision on benefit entitlement. This decision is straightforward if the medical evidence (any evidence supplied by the claimant's own GP (Med4 and IB113) and the advice

of the approved doctors (IB85)) corresponds with information in the claimant's questionnaire (IB50). However, if there are inconsistencies, the decision maker will weigh up all the evidence before arriving at a decision on benefit entitlement.

### 1.4.3 Claimants with diagnoses of mental illness

A claimant who appears, on the evidence available, to have a mental health condition will be referred to an approved doctor for advice before an IB50 questionnaire is issued. Those with severe mental health conditions will be exempt from the Personal Capability Assessment process and treated as incapable of work. Claimants with a mild or moderate mental health problem will be sent the questionnaire (IB50) so that any other physical and sensory problems can be taken into account, as well as the effect of the mental health condition.

### 1.4.4 The Better Medical Evidence Gathering pilot

The Better Medical Evidence Gathering pilot was designed to test alternative arrangements for the provision of medical information that may reduce the problems identified with the current arrangements, bring improvements and increase efficiency. The objectives of the pilot were to identify arrangements for providing medical evidence that might:

- improve approved doctors' ability to identify the cases that meet the requirements of the medical testing process more quickly and without recourse to full medical examination;
- improve decision makers' ability to make allowance or disallowance decisions based on medical evidence, with greater confidence and with fewer decisions overturned at appeal;
- reduce the burden of Incapacity Benefit-related paperwork on GPs;
- reduce inefficient use of medical resources, particularly at examinations.

In order to achieve the above objectives, the current system of collecting medical evidence from GPs via the IB113 and Med 4 forms was replaced with a system where approved doctors sought access to the claimant's GP case records for the last five years and prepared an extract of relevant information onto a new form SB2. Table 1.1 shows the types of medical evidence available at different stages of the decision-making process and how this differed between the current and the pilot arrangements. The basic decision-making process (see Figure 1.1) remained the same.

**Table 1.1 Medical evidence: differences and similarities between the current and pilot arrangements at different stages of the decision-making process**

	Current arrangements	Pilot arrangements
Advice whether to exempt from PCA process	Application form (SC1) Case file IB113	Application form (SC1) Case file SB2
Scrutiny	Application form (SC1) Case file IB113 or Med 4 IB50	Application form (SC1) Case file SB2 IB50
Decision maker assessment of whether claimant meets threshold for Incapacity Benefit	Application form (SC1) Case file IB113 or Med 4 IB50 IB85	Application form (SC1) Case file SB2 IB50 IB85



The pilot began in January 2002 in the Sheffield and Rotherham area. All GP practices were invited to participate voluntarily. Claimant participation was sought over a ten-month period, which extended beyond initial expectations in order to generate sufficient claims under pilot arrangements to enable evaluation. Both those making a new claim for incapacity benefit and those who were having their claim re-assessed were invited to take part. Claimant agreement to take part in the pilot was sought on the incapacity benefit application (form SC1) and, for current claimants facing a PCA, on their questionnaire (form IB50). Claimants who did not opt out, and GPs who voluntarily agreed to take part, went forward into the pilot.

GP case records, or photocopies, were required within 15 days, and were sent by secure courier to Managers and Process of Claims Ltd. (MPC)<sup>9</sup> for scanning on to a CD and forwarded to the Medical Services Centre in Leeds. Case records were returned to GPs within three days (or immediately on request in case of emergency). It was possible for computerised records to be transferred as a print-out of the last five years' records. GPs received payment for the work involved in preparing IB113 reports for DWP medical officers and Med4 statements for patients through their overall NHS remuneration. In recognition of the potential additional work for the GPs and their staff, GP practices received an honorarium of £10 for each patient whose original notes were transferred during the pilot and £20 if photocopies of the notes were provided.

An approved doctor received the CD of the GP records and extracted relevant medical evidence to a new report form (form SB2). This report form was then available to provide evidence at the appropriate stage of the PCA medical advisory process (potential exemption, scrutiny and examination). The SB2 was also available to the Jobcentre Plus decision maker who made the decision on benefit entitlement. According to the information sheet prepared for GPs (DWP/Medical Services, V5, Jan 2002) the information extracted from the case notes was confined to:

- whether the claimant had a specific bodily or mental disease or disablement;
- whether conditions for exemption from a PCA were met;
- assessment of function restriction/limitation, arising from the disease or disablement;
- whether legally defined 'exceptional circumstances' applied; and
- the functional outlook or prognosis.

## 1.5 The framework of the report

Chapters 2 and 3 examine the GPs' and claimants' views and experiences of the pilot arrangements respectively. Chapter 4 investigates the administration of the pilot arrangements in Jobcentre Plus offices and in the Leeds Medical Services Centre. Chapter 5 explores the use of GP records for making decisions about exemption and for extracting information onto an SB2 form. In Chapter 6 we look at how the extracted information is used by EMOs and by decision makers. Chapter 7 presents a number of issues arising from the study that might inform future policy for the collection of medical evidence, and presents the conclusions of the qualitative evaluation of the pilot.

Appendices provide full details of research methods and the analysis of data. Appendix A includes details of the characteristics of the claimants who took part in the research. Appendix B contains topic guides used in interviews with research participants. Appendix C contains copies of letters sent to GPs and claimants. Appendix D provides a full explanation of the administrative context within which incapacity benefit claims are decided.

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<sup>9</sup> Towards the end of the pilot MPC were renamed Elision.

## 1.6 Note on terminology

Medical practitioners play a variety of roles in the administration of incapacity benefit. These are referred to in this report as ‘approved doctors’. The key role of the approved doctor in the Medical Evidence Gathering Pilot included:

- preparing a data extract from GP case files (on form SB2);
- advising decision makers on paper evidence for exemption/scrutiny cases;
- advising decision makers following an examination of the claimant (when they act as an Examining Medical Officer (EMO)).

Incapacity benefit approved doctors may be:

- employed by the DWP directly (in DWP Corporate Medical Group);
- employed by SchlumbergerSema Medical Services (the company contracted to provide Medical Services to DWP); or
- subcontracted to Medical Services.

In relation to medical evidence gathering for Incapacity Benefit, NHS general practitioners’ terms of service require them to provide certain information to a DWP ‘medical officer’ on request. The relevant legislation defines that a medical officer may be a doctor employed by DWP directly or by an organisation contracted to provide medical services to DWP. Doctors such as NHS general practitioners, who provide advice and statements of incapacity (so-called sick notes) to their patients as part of their clinical practice are known as ‘certifying medical practitioners’. NHS GPs have a contractual obligation to provide such statements to their patients and to provide information subsequently requested by a DWP medical officer (DSS/DWP, 2000).



## 2 Views and experiences of GPs and practice staff

Our analysis begins by presenting the views and experiences of GPs and administrative staff in 29 practices in the Sheffield and Rotherham area, of which 17 had agreed to take part in the pilot arrangements and 12 had declined. Appendix A presents details of the selection and personal characteristics of the GPs in this study group and key characteristics of the practices in which they worked. The researchers usually spoke to the senior partner; in four practices they were asked to speak to the practice manager, as the person who knew most about the pilot.

Additional research interviews, with administrative and clerical staff with day-to-day responsibility for dealing with the requests for medical notes, took place in ten of these practices taking part in the pilot.

The first part of this chapter is concerned with GPs' initial views of the proposed new arrangements, and decisions made about whether to participate. The second part is concerned with the impact of the pilot arrangements for GPs and practice staff in those practices which took part in the pilot. Part 3 explains overall views on the pilot arrangements, as they emerged by the end of the research interview. GPs and practice staff weighed up advantages and disadvantages now perceived, after discussion with the researcher and, for some, through experience of being in the pilot.

### 2.1 Taking part in the pilot

#### 2.1.1 Awareness and understanding

At the beginning of the research interview, not all GPs could remember receiving the DWP invitation to take part in the pilot. This was especially the case among GPs who had declined to take part (non-participant GPs). Feeling '*overwhelmed*' by requests to take part in research meant that, unless the subject matter was of particular interest, GPs might pay little attention. Practice managers, who remembered the matter being discussed in practice meetings, were sometimes the main source of information about the initial reactions of GPs to the request from the Department.

Those who could remember requests to take part in the pilot reflected on their initial understanding of its purpose and what would be involved. Again, there was hazy recall among some of the non-participants. All GPs who could remember the process of considering the new arrangements and whether to participate said that there had been some consultation with other practice staff. It was common to put the matter on the agenda for the fortnightly or monthly practice meeting, and take

account of the views of other partners, the practice manager and sometimes other senior administrative staff, who would have day-to-day responsibility for dealing with the arrangements. It appeared that the views of the practice manager could be highly influential in encouraging participation.

The main aim of the pilot, as recalled in retrospect, was generally seen to be to reduce the workload of GPs. The pilot would show whether a potentially time-consuming task for GPs could be achieved in a different way. A small number of GPs, who had been especially interested in the pilot, remembered other aims: to provide better information about eligibility for benefits and to reduce the number of medical examinations. Among this group were GPs who were active members of Local Medical Committees and said that the pilot had been discussed at meetings they had attended. One GP suggested that the pilot could be seen in terms of helping people back to work, but did not elaborate on this.

Doubts about the purpose of the pilot were expressed by one GP who thought there would be some underlying '*political or financial goal*' which would not be in patients' interests.

In deciding whether to take part in the pilot, GPs and practice staff weighed up possible advantages against any concerns.

### 2.1.2 Agreeing to take part

Among the group of practices which had decided to participate in the pilot, some saw only advantages in the new arrangements. Others had some initial concerns but these were resolved.

The main attraction of the proposed new arrangements was that they could save GPs' time, and reduce the number of forms they had to fill in. This duty was generally disliked, even if perceived as part of the GP's job. This was not just because of the time involved, but also because doctors often felt they could not answer questions asked for benefits purposes, or felt that some of the questions were inappropriate for a GP whose main responsibility was treating patients, dealing with their illnesses and maintaining health.

Additional work likely to fall on practice administrators and clerical staff had been considered but, in this group of participants, was perceived as unlikely to be high, and certainly manageable. Practice managers who had experience of similar arrangements of collection and return of patients' notes for the miners' compensation scheme had not met problems here.

Not all participant GPs remembered thinking about possible outcomes for patients when they were considering whether to take part in the pilot. Those who did said they thought the new arrangements might lead to greater justice for patients, who were more likely to get what was rightfully theirs on the basis of more appropriate detailed information. Some GPs said that they did not have time to write much on the IB113 forms. Some said they felt slight unease about what they wrote, recognising that they were not always '*dispassionate*'. Examination by a third party might give a more balanced picture for benefits decisions, or, at least, no worse than the assessment possible from the GP-completed IB113. One GP thought that the pilot arrangements would mean quicker assessments, explaining that if GPs in his practice were busy or on holiday it could take three or four weeks to complete and return an IB113 form.

Apart from specific advantages perceived, some GPs said that they had been influenced by more general views. For GPs who felt it was time to review the provision of medical evidence for benefit purposes, this pilot was one step forward in the right direction. Another positive influence on deciding to take part was feeling definitely in favour of research and development for the advancement of general practice, and wanting to be part of this.

A number of initial concerns were recalled, but these had been addressed in practices which agreed to take part. Some GPs and practice managers felt it essential that patients' notes and records were always available in the surgery, in case patients came in for consultation, needed treatment or repeat prescriptions. A number of medical and non-medical staff might require immediate access to patients' notes. This concern was addressed by the photocopying option, by the Department's reassurance of immediate return of notes if required or, as explained in Section 2.2, by development in some practices of administrative processes to avoid problems arising.

It was considered important that patients had given their informed consent, and there were some initial concerns about how this was going to be handled. GPs in participating practices had been satisfied by explanations from the Department of the way in which patients agreed to their notes and records being used.

There were also concerns about the confidentiality of information about patients which left the surgery. Initial reassurance came from telephone explanations about how the data would be transported and dealt with, which courier firm would be involved, and which Medical Services staff would see the case notes. Again, administrative processes were introduced in some practices to help maintain confidentiality, as explained in Section 2.2.

One GP remembered wondering whether taking part in the pilot would result in additional demands on the practice in terms of reporting back. Being told that any such further participation would be voluntary had been reassuring.

The payments for participation offered by DWP were generally not very important in decisions to take part. Practices which opted for photocopying sometimes said they thought in retrospect they had not thought hard enough about the payment levels.

### 2.1.3 Deciding not to take part

As explained earlier, not all non-participant GPs could recall being invited to take part in the pilot, and some did not know why their practice had decided against participation. Also in the group were GPs who explained that the invitation had come at an awkward time, coinciding with a change of practice manager or installation of a new computer. In these circumstances, most external requests which would require extra work or different ways of working for administrative staff were being turned down. Had their invitation come at a different time, it might have been considered differently. There was, therefore, a relatively small number of GPs who remembered declining to take part in the pilot on matters of principle or because the pilot compromised normal ways of working. Those who did remember had strong views, which were often based on negative personal experiences.

The possibility that records would be out of the surgery when required could be a strong negative influence, as could potential danger of loss or damage in transit, or return of notes and records filed in the wrong order. Both GPs and practice managers saw risks here. In these practices the photocopying option which might address this concern had appeared to require considerable additional administrative resources. In practices in which administrative staff were '*already overloaded*' or premises cramped, extra photocopying was not wanted. Interestingly, in some of these non-participating practices, experience of the miners' compensation scheme was that staff came to the practice and scanned notes and records themselves, using their own equipment and paper. This seemed a better model, and thus did not encourage participation in this pilot.

It was not always clear why the DWP had considered there to be any potential gain for practices. The level of additional payment, in the form of an honorarium for participation, appeared to offer them little or no financial incentive. Some GPs also thought the overall costs of the proposed new arrangements would be higher for the Department.

There was concern about who would have access to the records once they left the surgery. One GP remembered previously seeing patients' incapacity benefit case files lying on the floor in a medical examination centre. His view was that the pilot was unethical and breached the commitment given to patients about their confidentiality. There were general concerns about whether patients would be giving consent, and if they would, whether they would fully understand the range of information about them that would be available to the approved doctors (DWP medical officer). It appeared possible, to the researchers, that some decisions not to take part had been made quickly on the basis of concerns about informed consent and confidentiality, without full understanding of how and when consent was sought, or how notes and records would be handled.

Another strong view was that the GP is the best person to provide the medical information required. One GP who had experience in a separate capacity of using medical information drawn directly from GPs' records, felt that the quality of some records was so poor that a system based on such records would be unworkable. One practice had already gone a long way towards development of what seemed a better way of providing information - using software templates to lift appropriate data from electronic records to fit different benefit forms. For them, the pilot arrangements seemed a step backwards.

As already pointed out, we do not know how far some of the concerns were based on incomplete information or misunderstanding, or whether, and how far, any staff pursued initial concerns or sought further information before declining to take part. We do know from interviews in participating practices that phoning for clarification, further information or reassurance was often important in agreeing to take part.

## 2.2 The impact of taking part

Not all the practices in this study group who had agreed to take part in the pilot had actually received requests for records thus far. The GPs concerned (from three practices) were surprised about this, and there was some disappointment that they had not had an opportunity to test the new arrangements themselves. We do not know the reason why no requests had been made.

Those 14 practices which did have experience of providing medical information under the pilot arrangements reported collection of between two and 50 sets of records by the time of the research interview.

### 2.2.1 The impact on GPs

There was mixed evidence of any impact felt directly by GPs. Some said they had noticed no impact. In terms of their overall administrative work they felt two or three fewer IB113 forms per week could easily go unnoticed. However, such GPs readily acknowledged that their paperwork had been reduced if fewer IB113 forms had been passed to them for completion, even if they had not noticed this.

Reduction in workload had been noted by a GP who was a single practitioner in what was described as a deprived area, who reported normally receiving six or seven IB113 forms each week. These seemed a heavy burden and the practice was sometimes unable to meet requests for return in seven days. The reduction in IB113 requests was an improvement for this GP who hoped the arrangements would continue. A GP in a multi-partner practice in an area of relatively high employment had also noted a reduction in paperwork. This GP generally dealt with two IB113 forms each week, and each took 15 minutes to complete. For this practitioner the pilot arrangements took away an '*irritating and time-consuming administrative task*'. In the large multi-partner practices the work of completing

IB113 forms was shared out in different ways. Where there was a rota system and most of the weekly incoming IB113 work fell to one GP at a time, this could take more than two hours. Not surprisingly, a GP within such a practice had noticed a welcome reduction in this kind of work.

GPs reported no negative impacts for themselves of taking part in the pilot, and none knew of any negative impacts for patients. GPs in multi-partner practices thought they would have heard about any such outcome from their colleagues. There was some surprise that there had been little feedback from patients. Some GPs had expected patients to mention the new arrangements, but there was only one such report, of a patient who remarked that the benefit decision had been made more quickly under the pilot arrangements.

There was one report of the situation arising that had initially given some GPs concern, that of a patient coming for an appointment and repeat prescription while her notes were away. This was not reported as a problem however. The GP concerned knew the patient's circumstances; the prescription records were on the computer and it was not necessary to ask for immediate return of the notes.

GPs often said that their practice manager would have a fuller picture of the overall impact for the practice. It was expected that additional work had been created for the clerical and administrative staff, but not all GPs had yet discussed this with the staff. The experience and views of administrative staff in the practices is reported in the following section.

### 2.2.2 The administrative experience

Most practices in the study group, who had experience of dealing with requests for medical records under the pilot arrangements, had chosen to send the actual records, sometimes with additional print-outs from computerised records, depending on how far the practice had moved towards computerisation. The study group did include some practices which had opted to send photocopied notes and records, rather than the original documents, and one so-called 'paperless' practice which was sending only a print-out of electronic records.

In terms of administrative work required, this was variable depending partly on the number of requests coming to the practice, but mainly on whether practices were sending actual records or photocopies. The process was quickest and easiest for those practices sending actual case records. All these practices still maintained paper files for documents such as consultant letters and test results, and in some cases GPs' hand-written consulting notes. Practice managers or administrative staff found the paper files, and printed out whatever additional records were computerised.

A number of practices had introduced processes to avoid problems arising as a result of the notes being out of the surgery. Thus, in some practices, staff always checked to see if appointments or repeat prescriptions were due during the time the notes were likely to be away. Some practices routinely photocopied the last two consultation sheets, so that medical staff still had the most recent record if the patient needed attention. A number of practices had also introduced processes to help maintain patient confidentiality, for example, routinely removing notes made by non-medical counsellors and any reports made for solicitors or insurance companies. These additional individual processes were reported not to be time-consuming. It was often not realised by staff sending actual records that only those from the last five years were used in the medical assessment. When this was discussed, staff felt that separating notes from the last five years at the surgery would take extra time and be administratively cumbersome, requiring the need for new files or new filing spaces. They preferred to keep files together.

The general view of administrative staff, in practices which were sending actual records, was that this was relatively easy to manage and had not created problems for them. They felt the administrative



work was probably not taking more time than would otherwise be spent dealing with IB113 forms, in terms of retrieving patients' records, distribution of records and IB113 forms to GPs, monitoring progress, returning completed forms and refiling the records. It was not hard to fit the pilot arrangements into existing work schedules, which meant that staff could usually respond quickly.

Practices in this study group which had opted to send photocopies or print-outs, reported a rather different experience. The task of photocopying and dealing with the printing or scanning machines was generally dealt with by more junior staff. Some large practices employed part-time clerical staff just for photocopying or printing duties. The work for the pilot arrangements waited its turn for attention, along with requests from solicitors and insurance companies. Prioritising any photocopying work involved additional supervisory input, which was not always possible. For the staff doing the work, opening paper folders, removing staples and envelopes, photocopying, restapling and replacing material in correct order could be a lengthy business. In paperless offices, printing out individual sheets of scanned material could also be time-consuming. Clerical staff said dealing with one set of records usually took between 15 and 30 minutes, but could take up to one hour. Practices which were sending photocopies or print-outs knew that only five years' records were required and none were sending more than required.

Views varied about the length of notice given for collection. Two days was sufficient for practices sending actual records. This amount of notice was said to be insufficient by practices opting for photocopying or sending only print-outs, who said they needed four to six days to fit the task into normal work schedules.

The arrangements for collection and return of records generally worked well. No problems were reported in terms of delayed return, losing material or sending it back in an unsatisfactory condition. Practices were satisfied with the courier service, whose staff telephoned in advance of arrival, dealt courteously and appropriately with reception staff and kept a low profile in the surgery waiting area and car park. One practice which had arrangements for collection and delivery at two sites had wondered initially whether this would lead to confusions but was pleased with the efficiency of the courier service.

Experience of the work involved in implementing the pilot arrangements led to the view among some practice managers that the honorarium of £20 for sending photocopied records was insufficient. This amount was compared with £50 received as the minimum for photocopying records for private medical insurance purposes. It was known that the payments for participating practices were to be made only at the end of the pilot period, but there was some irritation that only through requests for payment had some practices learned that the pilot period had been extended from the original date.

## 2.3 Emerging views on pilot arrangements

Views on the pilot arrangements sometimes changed during the research interviews. During their interview some people gained apparently new information about the purpose of the pilot and the way that medical evidence was dealt with in determining benefit claims, and some misunderstandings were cleared up. Such new information influenced the reflections of the GPs and administrative staff on their experience of the pilot arrangements. One GP discovered during the research interview that, contrary to his initial expectations and preferences, actual records were leaving the practice.

Overall views on the new arrangements also depended on what people felt about the usual process of completion of the IB113 form. This section thus starts with a summary of GPs' views on dealing with IB113 forms.

### 2.3.1 GPs' views on the IB113 form

The IB113 asks the GP to provide factual information to the DWP medical officer (approved doctor) on the named incapacity benefit claimant. Payment for this work is included in GPs' overall NHS remuneration.

The general view among participating and non-participating GPs was that currently there were problems in seeking medical evidence to determine IB claims using the IB113. Filling in the form could be time-consuming. Generally, GPs said the form took about 15 minutes; those who said they liked to do this work '*properly*' said it could take 30 minutes to look at the records, decide what to write and fill in the form. Keeping abreast of the IB113 work sometimes meant taking the forms home to deal with in private time. One way of saving time was for nursing or administrative staff to fill in parts of the IB113 from patients' records. No GP interviewed said that they sometimes did not return the IB113 forms, but some with strong negative views about this work said they spent as little time on it as possible, and this could be just a few minutes for each form.

A view often expressed was that some of the questions asked on the IB113 were hard to answer, such as 'effects of the medical conditions on daily living'. GPs were irritated to be asked for information which they did not know. Some were concerned, however, that patients might be penalised by their answering 'don't know' or leaving blank spaces. Care was needed in providing answers on the IB113 in case the patient went to appeal and challenged what the GP had written. One way of dealing with this was to discuss with the patient how to fill in the form, but this was unusual and created even more work.

On the other hand, GPs who did know something about the patient's daily activities felt they were not always objective, because they tended naturally to act as '*advocates*' for their patients. It could be hard both to be fair to their patient and meet their responsibilities to the state. Some said that personal views inevitably crept in, such that an IB113 completed for a patient thought to be a '*genuine case*' was likely to contain information phrased in ways that might support the claim. On the other hand, when a patient was thought better able to do some work, the IB113 form was likely to contain only essential factual information set out succinctly. Some GPs saw the opportunity to influence the benefit decision as a result of what they wrote on the IB113 form as an advantage.

Some GPs felt their involvement in benefit decisions, by providing medical evidence on forms such as IB113, affected relationships with some patients who were angry when their claim for benefit was disallowed.

Different views among GPs on a number of the above issues contributed to a wide range of attitudes towards their provision of medical information on the IB113 forms. At one end of the spectrum were GPs who saw their work on benefit forms as part of their commitment to their patients and tried to be fair and accurate, sometimes despite insufficient time or irritation with the questions. At the other end were GPs who felt that they were not the appropriate people to ask for the information required, said they did not prioritise this work and sometimes did not take it very seriously.

### 2.3.2 Advantages and disadvantages of using GP records

Drawing on both their own experience and the discussion during the research interviews, GPs and practice staff who had taken part in the pilot weighed up the advantages and disadvantages.

The GP records were generally felt to provide fuller, more comprehensive information. This was likely to serve patients' interests better and lead to fairer decisions about benefits. In turn, the GP saved some time to spend on work which some felt more appropriate. A further advantage was that the new arrangements increased the distance between the GP and decisions made about entitlement, and thus reduced some potential for problems developing in the relationships with patients.

Disadvantages perceived by some practices sending photocopied material were that this created considerable additional administrative work, with insufficient remuneration under current arrangements.

There remained some concerns about releasing to third parties some kinds of sensitive information which was recorded in some patients' notes, for example information about social or marital problems, and convictions. This was linked to continuing concern about the level of patient understanding about material in full GP records and whether patients really understood what they were agreeing to. There was also continuing concern among both participant and non-participant GPs about the low quality of some GP case notes and records, especially from locums. Some hand written consultation notes were believed to be generally illegible.

As we might expect, non-participating GPs tended to continue to emphasise their concerns and the disadvantages they perceived. By the end of the research interview there was sometimes a reduction in concerns initially reported about issues to do with collection and return, as a result of greater understanding of options for transferring information. A request for records for the last two years might have led one non-participant GP to consider taking part more favourably, because recent records and notes were computerised. Other GPs, however, both participant and non-participant, felt a two-year period for assessment would be insufficient. They said that some conditions had long histories and this had a bearing on capacity for work.

When GPs, maintaining strong negative views about the pilot arrangements, were asked whether anything might change their mind, suggestions made included:

- evidence of better benefit decisions, at realistic cost for the Exchequer;
- evidence that patients wanted the new arrangements;
- specific written consent from patients (comparable to those prepared by solicitors);
- reduction of length of the period for which records were required to two years (thus enabling wholly electronic transfer procedure).

## 2.4 Summary

The pilot arrangements had been welcomed by GPs who saw opportunities for saving time and shedding an administrative chore, and a procedure likely to lead to a more balanced picture for benefits decisions, or at least no worse an assessment of their patient. GPs who had declined to take part had concerns about confidentiality, whether patients understood the implications of consenting to the procedure, and saw risks in loss of or damage to their records and not having continuous access in the surgery. Practices taking part in the pilot arrangements shared some of these concerns, but had resolved difficulties. Some had sought more information about how the records would be handled, and some had developed their own procedures to minimise practical risks or inconveniences. Practice managers were often of key importance in decisions made about participation in the pilot.

Not all GPs taking part had noticed any impact. Those who did were GPs practising on their own, GPs in areas of social disadvantage and those who tended to spend longer time in filling in the IB1 13 forms. The administrative and clerical staff with day-to-day responsibility for implementing the new arrangements had mixed views on the impact of the pilot. Practices sending actual records had found the process fairly quick and easy and no problems had arisen. In practices sending photocopied records and print-out from wholly computerised records, the additional work required was time-consuming and could be hard to fit into existing work schedules. As a result, it was not always possible to meet time requirements, and the payment was felt insufficient.

There was some evidence that GPs whose strong negative views had led to non-participation, might view the pilot arrangements more favourably with greater understanding about how the records were handled. Concerns remained, however, about confidentiality and informed consent.



## 3 Views and experiences of incapacity benefits claimants

This chapter presents views and experiences of the pilot arrangements of incapacity benefits claimants in the Sheffield and Rotherham area. The first two parts of the chapter explain what people understood about the pilot and why they decided to take part or not. Section 3.3 presents findings about people's general awareness of, and interest in, the process of medical assessment. Section 3.4 explains how they felt about their GPs, what they thought their medical records contained, and views on medical examinations. This sets the context for discussion of perceived advantages and disadvantages of the pilot arrangements, the subject of Section 3.5. The last part of this chapter presents claimants' overall views of the pilot. Appendix A explains the selection of the 32 claimants, whose views were sought for this part of the research, and provides a summary of their main characteristics. Twenty-two were recruited as participants in the pilot, and ten as non-participants.

### 3.1 Taking part in the pilot

The main source of information about the pilot was the DWP explanatory leaflet sent with the incapacity benefit claim form or the IB50 questionnaire. The leaflet included a telephone number for more information. People were given the option to opt out of the pilot by ticking a box on their claim form if they did not want DWP to have access to their case notes. People who submitted their claim form before the pilot started, and who were not required to fill in an IB50 questionnaire, were sent an explanatory letter (PEG1), and the opportunity to opt in.

#### 3.1.1 Awareness of the pilot

Although incapacity benefits claimants were recruited to the research as pilot participants or non-participants, at the start of their research interview not everybody was aware of their relationship to the pilot. The letters inviting people to be interviewed and the researchers' introductions served as reminders, but not everybody recruited as participants understood they were taking part and some recruited as non-participants believed their claim was being dealt with under new arrangements. Even after prompting there remained a small group of people who appeared to have no prior knowledge of the pilot arrangements, and were thus unable to discuss decisions about taking part.

Those who remembered they were in some form of incapacity benefits '*experiment*' knew that they had given permission. Not all such people could now remember what the pilot involved, but most who remembered giving permission thought they had understood at the time.

Some people remembered generally that the pilot was about medical records, or going further into their medical details. Non-participants retained less understanding about the pilot than people who had agreed to take part, as we might expect. Those people who had retained clear understanding that the new arrangements involved DWP looking directly at the medical records held by their GP included men and women in different age groups, and people recruited as new claimants and re-referrals.

### 3.1.2 Sources of information about the pilot

Few people could remember receiving a leaflet about the pilot; there were more frequent mentions of '*a letter*'. It was frustrating when the letter did not enclose the leaflet to which it referred, as some people reported.

Telephoning for more information had not worked well for those who had tried this. People who had sought information in this way said that staff seemed poorly informed. (We do not know whether such people used the advertised helpline or telephoned local DWP offices.)

Written information could be important; some people read this carefully and thought it was useful. Those who had clearest recollection of reading about the pilot and considering the new arrangements were existing claimants being re-referred for a PCA who agreed to take part. We might expect that some people who already had experience of the medical assessment procedures would be particularly interested in the idea that things might be done in different ways. Among the new claimants, not everybody who could remember receiving written information had looked at it carefully. Knowing their medical records would be used in the assessment for benefit could be all the information needed to decide whether to take part.

Those who remembered making a decision about taking part had known that participation was voluntary, although we see in the next section that some people thought refusal would attract attention. Nobody remembered giving thought to whether their GP was taking part in the pilot, but people were interested in this issue when the researcher raised it. There was some surprise that GPs could also choose whether to take part. Some people thought that if claimants wanted to take part in the new arrangements their GPs should be required to participate.

## 3.2 Deciding whether to participate

As explained, people did not need full understanding of the details of the pilot in order to agree to take part.

Reasons reported as influencing agreement to take part included:

- hoping to avoid a medical examination;
- hoping for quicker and easier administration;
- believing that DWP would be suspicious of people declining to take part;
- welcoming an opportunity to '*show willing*';
- having '*nothing to hide*' and thus no reason to decline;
- believing a '*full picture*' from medical records would help distinguish genuine and fraudulent claimants;

- believing medical records would help educate DWP staff about mental illness;
- believing that advances in society required readiness to try new things;
- general support for policy pilots and public consultation.

These reasons for taking part fall generally into two groups: possible direct consequences for themselves and other claimants, and perceptions of the pilot arrangements as a generally better way of doing things.

Hoping to avoid being asked to go for a medical examination could be a powerful influence. Previous bad experiences at medical examinations meant that some people did not want to undergo another. Others who feared being asked to go for a medical included people with mental illnesses which made it hard for them to leave home or talk to strangers. They believed such problems might be interpreted as non-cooperation, leading to loss of benefits. Their hope was that their medical records would provide all the information required for DWP to make a decision without calling them for a medical examination.

Apart from the medical examination, some people thought that the administrative process would be generally simpler and quicker under the pilot arrangements. Not having to go to the GP for a Med4 was attractive. Others did not identify specific elements in the claiming process but had a general feeling that it might all be easier under the pilot arrangements, especially people who had previous bad experiences of administrative muddle and delay.

Another reason for taking part was belief that DWP would be suspicious of people who opted out and it could seem better not to attract attention. This had led to some people feeling some pressure in agreeing to take part. On the other hand, some people welcomed an opportunity to demonstrate their readiness to take part. People with different kinds of mental illness said they wanted to be seen to be ready to cooperate with DWP to reduce the kind of stereotyped stigma and suspicion attached to their illness.

Just having '*nothing to hide*' and, thus, no reason not to take part could be sufficient to agree to participate. Some people had not bothered to read all the information or think much about it; some who had been more interested saw no particular consequences for themselves. There then seemed no reason not to give permission, although one person observed that the way agreement was sought appeared designed to make it easier for people to agree to take part than not.

Perceptions of the pilot arrangements as a generally better way of doing things included the belief, often expressed, that the evidence in medical records would help to distinguish 'genuine' from 'fraudulent' claimants. Another view was that if more DWP staff looked at real medical records, they would understand mental illness better. Some people observed that society would not move forward unless people were prepared to try new things, and one person in particular strongly supported the idea of pilots and trials with public consultation, as a good way for a democratic government to develop policy.

The strength of such beliefs and feelings varied considerably between individual people. A person who feared being asked to go for a medical examination and was confident that her medical records showed she could not work was making a strong positive choice in agreeing to take part in the pilot. By contrast, some people could think of no reason for or against participation and attached little importance to the matter.

Few people were interviewed who could tell the researchers why they had decided not to take part in the pilot. Ten people were recruited to the research as pilot non-participants, some of these did not



remember being invited to take part, as explained previously, and one person believed he had given his permission and was taking part. For some people it appeared that the decision not to participate was effectively made by third parties. People making a new claim, who had received help with form filling from advice workers or hospital staff, said their adviser must have decided against their taking part, although they could not remember having discussed this. One person who could remember talking about whether or not to take part asked his GP about it. He said that the GP suggested it might be easier to send the Med4, and since he was already at the surgery this would be no trouble.

Among the small number of people who had decided themselves that they preferred not to take part, the following factors were reported as influential:

- objections on grounds of confidentiality;
- mistrust of DWP use of information in GP records;
- belief that GPs would get '*blamed*' if patients lost benefits;
- perception of administrative problems;
- belief that participation would result in additional demands on claimants.

There was some objection to the pilot on the basis that GP notes and records should be confidential between doctor and patient and not available to other people. A person expecting his GP records to be used in a law suit thought they should not also be used for other purposes. Linked to issues of confidentiality was some mistrust that DWP would use the information in the notes solely for the purposes proposed, but would take the opportunity to look for reasons for denying people benefits. Some thought that people who were not satisfied with the outcome of their assessment would be likely to blame their GP, if the decision was based on the GP's records. Administrative problems perceived included extra work for office staff in the surgery and possibility of loss of the records while they were out of the surgery. There was some feeling that agreeing to take part would bring additional demands on claimants and unwanted attention in some way, perhaps additional callers at home, or extra requests to visit Sheffield offices.

It is important to say again that these reasons for not taking part came from only a small group of people. The person who argued most strongly against the pilot, drawing on several of the above issues, had actually been recruited to the research on the basis that he was a pilot participant and it was not clear to the researcher what his status was in relation to the pilot.

As we report below, some of the non-participants subsequently told the researcher that their decision might have been different had they known more, or understood correctly, about the pilot arrangements.

### 3.3 Awareness and understanding of the process

In order to explore people's understanding of the process of assessment, the researchers asked what they thought happened the last time they had dealings with DWP about their incapacity benefit. For the participants, this was the claim made under pilot arrangements; for non-participants, the claim made under the usual arrangements.

Not everybody was interested in what happened. Those who made suggestions thought staff would look at what they themselves had written on the forms, and decide whether to seek some medical information as proof that they were entitled. Only rarely did people mention a contributions or income check. The kind of medical information DWP needed in order to decide entitlement was

expected to include details about past health, history of illness and treatment, current medical circumstances and the effects on their daily lives.

As to where DWP was likely to seek such information, most who had views suggested the GP. People who had been in hospital, were receiving out-patient or psychiatric care, attending pain clinics, diabetic clinics, drug rehabilitation centres or eye hospitals felt that the most appropriate medical information for the DWP was held by consultants or other health specialists. Some felt that DWP would write to their consultant, but not everybody was confident that this was part of the process. Wondering if DWP might deal with their claim solely on the basis of medical information supplied by a GP could be a concern. A small group of people, participants and non-participants, thought that the GP was not approached again for the incapacity benefit claim, but that the primary medical evidence was the number and contents of sickness certificates issued.

Other suggestions of possible sources of information included occupational health personnel or managers at work. There was also a belief that DWP would draw on medical information already supplied, for example looking across previous sick notes, or reports for claims for industrial injuries benefits and allowances.

Views varied as to which DWP staff had responsibility for collecting the information and making decisions and how this happened. A few people mentioned the points system or '*formula*' but this was not well understood. Some suggested decisions about entitlement were made by a '*panel*', '*board*' or '*jury*', expected to include doctors, DWP personnel, or possibly solicitors. Medical examinations were generally thought to be part of the overall process, but few had a full picture of how the medical fitted in. It was generally thought that assessment '*panels*' and medical examinations were located at centralised offices, and suggestions included Sheffield, New castle and Leeds. As we might expect, long-term incapacity benefits recipients and people whose relatives also had histories of claiming incapacity/invalidity benefits had the best grasp on the overall procedures.

Pilot participants, who had previously been assessed under pre-trial arrangements in the current or previous claiming spell, perceived few differences in the processes experienced thus far, although some had noted not having to get a Med4.

### 3.4 Relationships with GPs, perceptions of medical records, and views on medical examinations

We would expect claimants' views of the new arrangements to depend partly on their relationship with their GP and how carefully they expected the GP to fill in benefit forms about them. Views might also depend on what people thought GP records contained and how medical examinations fitted into assessments. This part of the chapter presents findings on these issues, to inform understanding of claimants' overall views about the pilot arrangements.

#### 3.4.1 Relationships with GPs

As we might expect, there was wide variation in people's reported relationships with their GPs, in terms of: length of the relationship; frequency of and reason for contacts; continuity of contact in multi-partner practices; and satisfaction with the care provided.

At one end of the spectrum were people who said they went to the surgery only for repeat prescriptions, rarely saw the same doctor twice, and did not rate the GPs very highly. At the other end of the spectrum were people who visited, at least once a month, a respected GP whom they had known from childhood. Similarly, there was wide variation in people's expectations and experiences

of discussing benefits and work with the GP; their confidence in the quality of the GP's records and general record keeping; and their own assessment of their GP's commitment to careful reporting on benefit forms.

### 3.4.2 Perceptions of medical records

Everybody had seen their GP making notes during consultations, either handwritten or on the computer, and most people had seen a 'file' or 'folder' for storage of notes and other items about them. Nobody in the study mentioned ever having asked to see notes kept about them.

There was variable knowledge about, and interest in, what else might be in the file. Suggestions included correspondence between the GP and hospital consultants including details of investigations, operations, treatment and progress; results of tests done at the surgery and in hospital; X-rays; prescription records; appointments with psychiatrists and counsellors, and records of work absence. Some people wondered how paper records were linked up with computer records in the surgery, or whether the records and notes were ever weeded out, to make space by getting rid of unwanted information.

While some were confident that their medical records held by the GP went back to their birth and were transferred as they moved home or changed their doctor, others were less sure that their current GP had a full historical record.

### 3.4.3 Views on medical examinations

Although new claimants had no recent experience of a medical examination for incapacity benefit some had been for medicals in previous claiming spells. Most recruited as re-referrals remembered a previous medical for Incapacity or Invalidity Benefit. In addition, some people recalled medical examinations for Disability Living Allowance or industrial injuries benefits. Some had clear memories of what parents or spouses had told them about their medical examinations. As expected from previous research, people drew on all such experiences and accounts when they discussed the place of medical examinations in assessments for incapacity benefits.

There was a wide range of feelings about previous personal experiences of medical examinations, linked to benefit outcomes and how people felt the examining doctor had treated them. Practical problems were also mentioned including the difficulty of the journey and budgeting in advance for the cost of travel. This study was not designed to explore fully respondents' experiences of medical examinations. Rather, the focus was on people's perceptions of how a medical examination fitted into the assessment for benefit, and the role of any medical information about claimants provided for the examining doctor.

There was a widespread belief that everybody receiving incapacity benefit was eventually asked to go for a medical examination. Others thought there was a selective process in which some people were more likely to be asked to attend, although the criteria involved were not clear. A few people suggested that the requirement for a medical was linked to the length of the claim in some way. Suggestions here were '*so many weeks after claiming*' and then '*every 12 months*', or just simply when people have been off work for a long time, or '*seemed to be getting better*'.

There was widespread acceptance of the importance of medical examinations in the assessment of incapacity benefit and support for the principle that everybody should have a medical examination eventually. Underlying this was a belief that deciding whether a person's condition prevented them from working could only be made properly by seeing the person and talking to them about '*what was wrong*' and how they felt. Even people who were anxious about being asked to go for a medical, and

people who had previously had bad experiences and disappointing outcomes, could support in principle the idea of a medical as an important part of the decision process.

There was also belief that a medical examination would help identify people making fraudulent claims.

Those who felt that medical examinations would be unhelpful for their own claims included people with symptoms of mental illness which would prevent them from going to an appointment, or communicating with the doctor when they got there, and who feared subsequent loss of benefit. A small group of people thought that a short medical was insufficient for an unfamiliar doctor to assess their condition, especially when this varied, or was complex.

The need to conduct separate medical examinations for different state benefits such as Incapacity Benefit and Industrial Injuries Benefit was believed to be a waste of time and resources.

There was general support for the examining doctor to have available as much information about the claimant as possible, and this included information from the person's GP. Those who believed that the fullest picture of their condition and its effects lay with their hospital consultants felt it was important for the examining doctor to have this kind of information.

When asked directly if it would be better for the examining doctor to see their actual GP records or have the GP's written opinions, most people opted for the actual records on the basis that these would provide the fullest picture, and that medicals would be shorter and more fitting if the doctor had full information in advance. There was, however, some scepticism among people who had already had an incapacity benefit medical examination, that the examining doctor would actually read through lots of notes. Some were critical of what they had experienced as short examinations by doctors who appeared to know little about them.

A person who would prefer the examining doctor to read information from the GP written on a standard form rather than the GP records, emphasised the need for a personal opinion from medical personnel who knew her history and current situation.

### 3.5 Advantages and disadvantages of the pilot arrangements

In order to get informed opinions about the pilot arrangements, towards the end of the interview the researcher summarised the main differences between usual arrangements for collecting medical evidence and the arrangements in the pilot. The emphasis was on the basic difference between asking the GP to send medical information by writing on a form and asking the GP to send notes and records. This served to confirm people's understanding, correct misapprehensions or increase their knowledge. For those who had little prior understanding or less interest in procedures, it could be hard to absorb new information of this kind during the interview, and misunderstandings and confusions remained among some of the respondents. It is important to remember this in considering claimants' overall views on the new arrangements.

Some people saw only advantages, or expressed only negative views. Others identified advantages but expressed some concerns or qualified their comments with reference to possible disadvantages.

### 3.5.1 Positive views

Claimants in both the participant and non-participant groups expressed positive views about the pilot arrangements. There was no systematic difference in the views of new and re-referred claimants. Advantages identified spontaneously included anticipated effects for themselves or other claimants and for the DWP, and effects for GPs.

The advantages for claimants and the DWP were that staff making decisions about benefits would have a fuller picture of the claimant's condition and its effects. There would be less danger of GPs omitting essential information, and important information from hospitals and consultants would all be available. The GP records would demonstrate change in someone's condition over time, which might be important.

With a '*full picture*' and more '*proof*' from the GP records, benefits staff would be better able to make the right decisions. This meant that they (the claimants themselves) would be more likely to be identified as properly entitled to incapacity benefit, and there would be no doubt about how ill they were (this latter point was emphasised especially by people with mental illness). The full picture from the GP records was also more likely to identify people making fraudulent claims (other people who were able to work) and would prevent claims being decided on the basis of information written by (other) over-sympathetic GPs.

Further advantages for claimants were that there would be no need for a GP appointment just to get a Med4. Fewer medical examinations would be needed, thus there would be fewer unnecessary demands on claimants and, some thought, less expense for DWP. If a medical was required, people would be asked fewer and more relevant questions because the examining doctor would already have full medical information.

Advantages were perceived for GPs in terms of a reduction in the work involved in getting information from the records or computer, remembering the patient and thinking what to write, and filling in forms. Less benefits work for GPs would mean more time available to spend with patients.

### 3.5.2 Negative views

Again, people in both participant and non-participant groups expressed some negative views about the pilot arrangements, and potential disadvantages were identified for claimants and the DWP, and GPs.

Issues were raised about confidentiality. There were concerns about who would have access to medical notes and records while they were out of the surgery. Not everybody trusted the DWP to use the records only for purposes of incapacity benefits.

Contrary to those who believed that the GP notes would provide the '*full picture*', some claimants thought that the GP records did not always reflect the full impact of a person's condition. Some matters were discussed with, and known by, the GP but not recorded (mentioned by people with mental health problems). Thus, in some situations, the GP would be able to provide more relevant information on the IB113 form than would be found in the records. Using medical information from GP records did not address the problem perceived by some who thought that information relevant to their claim was held by psychiatrists or consultants, and was not all in their GP records. People who discussed their condition mainly with counsellors or advice workers, or were dealing with their condition through self-help groups also thought that the relevant information for their incapacity benefit claim was not in their GP records. One person made the point that if DWP relied on GP records, those people who received all their support and help through self-help groups and alternative

therapies, and were trying not to rely on medication, only visited their GP for benefits certification. It might be easy for a third party looking at the GP records to interpret their lack of GP consultation and treatment as evidence that they were not ill.

One claimant who was well informed about the pilot arrangements felt that a period of five years was not long enough for seeking relevant medical information. Some conditions fluctuated, or developed in response to other earlier conditions, and this affected people's capacity for work.

One view was that neither the pilot arrangements nor the IB113 procedure addressed the problem perceived that some (other) people did not tell the truth to their GP.

There were some anxieties that even if the GP records were potentially a better source of information than information provided on the IB113 forms, DWP staff might not use it properly, for example using only information which would disallow a claim. One suggestion was that it would be time-consuming to examine properly a long medical record. If some benefits staff had time only to quickly scan the records, some relevant information could be missed. Another suggestion was that medical examinations would be dominated by the doctor reading GP records, leaving insufficient time to examine or talk to the claimant.

The pilot arrangements appeared to some claimants to introduce new forms of bureaucracy and the possibility of greater expense overall. One person suggested that if the pilot arrangements did lead to extra expense for DWP, charges might be introduced for claimants. If the GP records did provide better information for the DWP, this would mean more disallowances and more appeals. This could undermine GP/patient relationships, and more appeals would be a disadvantage for DWP.

Some claimants saw other disadvantages for GPs in extra work and expense in transferring the notes and records and the possibility of them being lost during transfer and use. There could be problems if records were not in the surgery when the patient needed treatment, and one person reported this experience herself. The point was made that some GPs just might not like their own notes being looked at in this new way.

As people weighed up advantages of the new arrangements against potential negative effects, some emphasised the importance of the quality of the information supplied to DWP, as well as the relevance. Only one person thought there would be any impact on their own relationship with their GP, but there were suggestions that it would be important for GPs to know in advance that claimants had given their consent to records being used in this way.

Views varied as to whether the new arrangements would be quicker, overall. Having less paperwork would save GPs' time, but the time input in the surgery might just be shifted onto administrative staff who had to deal with practicalities. It was also thought likely that staff using the medical information would need more time under the new arrangements, reading through all the different pieces of information, letters, tests and records. As a result, some people thought that it might take longer to reach a decision.

It was people who were recruited as pilot participants, who had been re-referred, who made the most sophisticated analysis of the advantages and disadvantages. They weighed up possible positive and negative impacts, seeing a number of arguments on both sides, sometimes illustrated from their own experience within and before the pilot.

## 3.6 Overall views of the trial

Before summarising claimants' overall views about the pilot it is important to remember that even at the end of their research interview some people still had little understanding of the medical assessment process, confusions or big gaps in their knowledge. Some people said they were just not much interested. What is presented here are the main patterns which emerged, and the issues of particular interest for policy makers. Some of the views expressed come, however, from relatively small numbers of people.

### 3.6.1 On taking part

By the end of the interview, most people recruited as pilot participants, including those who initially had not realised their own assessment was being dealt with under new arrangements, said they were content to have been included. There was a feeling that it was better to test new arrangements before introducing them for everybody, and that somebody always had to be '*the guinea pig*'. Some wished they had understood the process better, however.

Only one person in the participant group said if she had fully understood that only the last five years of records were examined she would not have taken part. She believed that a full picture of whether she could work depended on looking at her records and considering her condition over a longer time period.

Most people recruited as non-participants appeared more positive about the pilot arrangements at the end of the interview than at the beginning. Greater understanding about what was involved in the pilot helped to address some of their initial concerns or uncertainties. It was not unusual for non-participants to say that they would have been more likely to take part if they had understood more at the time.

### 3.6.2 As a technique for testing policy

There was some interest when people learned that the pilot was only taking place locally. Some were pleased that they had had an opportunity to help find out whether a new idea worked.

Learning from the researchers that GPs had been able to choose whether to take part drew some disapproval, as described earlier. It was considered wrong that some people, who might have wanted their claim dealt with under pilot arrangements, had been denied the opportunity.

### 3.6.3 On implementing the pilot arrangements nationally

By the end of the interviews, most people felt that it would be '*a good idea*' or '*all right*' to introduce the new arrangements nationally, although they thought some other claimants would not like it, especially people who felt it was invading privacy and those who were subsequently disallowed benefit. Claimants thought that some GPs were likely to be resistant, not wanting other people to look so directly at how they worked.

Some pointed out their views might well change when they learned the outcome of their recent assessment. Being disallowed benefit would tend to strengthen negative feelings about whichever arrangements had been used. The person who wished she had not taken part in the pilot said that if benefit was refused she would certainly appeal on the basis of being in a trial about which, she felt, insufficient information had been provided. Strong feelings against extension of the pilot arrangements also came from a man who thought that it would '*cause trouble*' by leading to more appeals and poorer relationships between GPs and patients.



Some people were puzzled about how the issue of individual consent would be dealt with if the pilot arrangements were introduced on a national basis or if they became compulsory. People emphasised the importance of ensuring confidentiality in dealing with the medical records and notes if the new arrangements were to be generally implemented. Speedy return and careful handling of notes taken from the surgery would be essential.

### 3.7 Summary

Not everybody in the claimant study group was aware of their relationship with the pilot. By the end of the research interviews some still had gaps in their understanding of the general medical assessment process, and the pilot arrangements.

Those who remembered agreeing to take part in the pilot were influenced by possible consequences for themselves, such as avoiding a medical examination, or not wanting to attract attention by declining to take part. Some liked the idea that seeing the medical records would help DWP distinguish genuine claimants. Only a small group of people remembered deciding not to take part, usually because of concerns about how the GP records would be used, or administrative problems perceived for GPs and themselves.

Claimants generally understood that GP records included consultation notes and records of prescriptions, and some also knew that letters from consultants and results of hospital tests were included. There was wide variation in claimants' reported relationships with their GPs, and their expectations of their GP's approach to providing information for benefits purposes, both of which could influence views of the pilot arrangements.

Both advantages and disadvantages in the pilot arrangements were perceived for claimants, DWP and GPs. Nearly all those who had taken part were content to have been included, and most of those recruited as non-participants appeared more positive about the pilot arrangements at the end of the research interview, when they understood more, than at the beginning. Most of those interviewed, who had a view as to whether the pilot arrangements should be introduced on a national basis, felt positively about this. These views might change when people received their decision about benefit entitlement.





## 4 Administering the pilot arrangements

### 4.1 Implementation in Jobcentre Plus

Within Jobcentre Plus, staff in the medical administration teams dealt with claims processed under the pilot arrangements alongside incapacity benefits claims being dealt with in the usual way. Group discussions with three teams of administrative staff, nearly 12 months after the introduction of the pilot, provided information about the effect of the pilot on the work of the processing staff, and further perspectives on the impact of the pilot on claimants and their advisers. Details of recruitment to, and conduct of, the group discussions are in Appendix A.

Most of the discussion with staff was concerned with differences in practice in processing claims under the pilot arrangements in comparison with usual ways of working, and the effect of these changes. As we might expect in the introduction of a new way of working, some problems did arise. Understanding what was happening provides useful pointers to ways of avoiding such problems should the pilot arrangements be introduced elsewhere. Drawing on their direct practical experience, staff gave their views on the main strengths and weaknesses of the pilot arrangements.

#### 4.1.1 The impact on working practices

Normally, the administrative work required in processing Personal Capability Assessments in Jobcentre Plus is largely computer driven. Staff work in response to what are called 'BF prompts' (Brought Forward), which indicate appropriate processing stages and time limits for individual claims. Staff use the computer to issue standard letters and forms, manage the administrative flows to and from decision makers and Medical Services, and, depending on outcome, withdraw benefit. Some reminder letters are issued automatically to claimants from whom a response is required, according to stages reached and pre-set time limits. It was decided that the pilot would rely on clerical procedures, and that any decision to extend it more widely would require consideration of supporting IT changes. No new computer programmes were inserted for processing and managing claims dealt with under the pilot arrangements.

Jobcentre Plus staff and the pilot project knew when the pilot was set up that the reliance on clerical procedures would mean that they would have to take more decisions themselves about processing, and do more clerical and manual work in dealing with claims under the pilot arrangements. They explained the impact of this. First, staff had to decide whether to deal with the medical assessment

under the usual arrangements or the pilot. This meant checking first whether that person's GP was taking part in the pilot. Staff had lists of GPs and practices which indicated which doctors were taking part in the pilot. It took some time to search through these lists, which were re-issued quite frequently because, staff understood, some GPs changed their minds about participation during the pilot. Finding the claimant's GP was not always straightforward; for example, if patients had seen locums or changed their address or if GP practices operated from more than one surgery. It was sometimes necessary to telephone surgeries, and this could mean having to explain the pilot to practice staff. Staff thought there was the potential for some errors in matching claimants to GPs, and deciding whether claimants were pilot participants or not. Claimants could change between the categories of participant and non-participant during processing, for example, if they changed their GP or changed their mind. Which category claimants belonged to was not always clear, and additional checks and telephone calls were required in order to make the right decisions.

Additional confusions arose when instructions changed, early in the pilot. For example re-referral PCA cases were introduced two months into the pilot, requiring some re-learning of procedures. A frustration which remained throughout the pilot was that there was no indication to staff of what changes had been made when lists of participating/non-participating GPs were re-issued, so they had to search through carefully themselves each time they received a new list.

When claimants were identified as potential participants, staff first had to adjust their computer programme so that the normal prompts were overridden, and then set new BF prompts to guide the process. They estimated that this took four or five times as long as setting prompts under the usual arrangements. The decision was then made, as usual, whether to deal with the claimant as a person with a mental illness or terminal illness who was potentially exempt. Under usual arrangements, and on behalf of the approved doctor (medical officer), they would issue the IB1 13 to the person's GP, for return to the approved doctor. Under the pilot arrangements, they sent the claimant's details and the GP's reference number by fax to Medical Services, a new component in the process.

In addition to the cases described above, new claimants who were potentially exempt, and those returned with advice from an approved doctor that the claimant was not exempt, were people who were potentially exempt but who had started their claim before the pilot started. For these people, staff issued a hand written PEG1 form with explanatory information about the pilot, seeking claimant agreement to take part. If positive replies were received, the consent was copied and sent to Medical Services by fax, with a tracking form SB1. Replies from claimants could take a long time, however, and sometimes came after the time limits had expired and the case was already being dealt with under usual arrangements. Staff thought that some people with mental illness, and some people with drugs or alcohol problems took a particularly long time to deal with letters from the DWP. If they did receive a consent to participation from a person whose claim they had already started to deal with under usual arrangements they tried as far as possible to intervene in the process, for example, sending a covering letter to Medical Services. This again caused additional work.

Some people making new claims came into the pilot by indicating consent on the application form. The next stage for non-exempt participants was to send them an IB50P, the questionnaire for self-completion. This was the usual form IB50 with an additional explanation of the pilot, and another opportunity to opt out. When these forms were returned, some claimants already notified as pilot participants had opted out (and vice versa) and had to be recategorised, with covering notes sent to Medical Services.

In addition to the additional clerical and administrative work described above, staff explained that if pilot cases took some time to process, measures initially taken to override the usual system prompts began to produce 'action overdue' prompts and prompts to alert staff to time limits running out. As

a result, their 'prompt load' increased considerably, and required additional work. In one office which reported low staff levels and other problems during 2002 the pilot had increased backlogs of work and sometimes seemed like '*an ongoing struggle*', even with additional resources. In all offices, it had taken some time to get used to the new arrangements.

When staff were asked what they thought had been the effect of the pilot on decision making there was some doubt that the pilot had led to more paper-based exemptions or fewer medical examinations, as hoped, although relatively low numbers of participants meant that it was hard to see definite patterns. In one office, staff thought that the pilot arrangements had probably delayed decisions<sup>10</sup> for claimants as a result of the additional processing components and extended time limits.

### 4.1.2 Perspectives from claimants

Telephone enquiries about the pilot arrangements from claimants and their advisers provide useful perspectives on concerns and issues arising for people whose incapacity benefit was being dealt with during the pilot period.

Enquiries were sometimes made in response to receipt of the PEG1 or IB50P. Some people wanted to know what would happen to their GP records when they went from the surgery and how they would be used. There were concerns that records would be dealt with in confidence and with care, and either returned or that photocopies would be shredded. Staff said that some claimants were pleased to hear that information in their GP records would be available to people making decisions about benefits. This was reported especially from some people with mental illnesses and some people expecting to be asked to go to a medical examination who said that better and fuller information about their condition and its effect would be in their GP records.

Staff also received telephone calls from people who did not understand the PEG1 form, seeking guidance from staff about whether they should agree to take part. Staff tried to explain the pilot arrangements and what would be involved, but tried to avoid influencing decisions. Some people telephoned to let staff know how much they disagreed with the proposed arrangements. Later in the process, some participants telephoned to find out whether Med4 forms were still required, and to sort out other confusions. Altogether, processing staff received an increased number of telephone calls from claimants during the pilot, and some of these required sensitive handling. There were, however, very few enquiries from GP surgeries, benefits advisers or health/care professionals. Each team could remember only one or two such enquiries during the pilot period.

### 4.1.3 Strengths and weaknesses of the pilot

Staff had initially been interested in the pilot, and keen to take part effectively, although concerned about the lack of computer programme adjustments for implementation. There had been disappointment and some surprise at what seemed a relatively low number of GPs agreeing to take part.

In the office, immediate managers had been supportive of staff engaged on the pilot, and it was agreed that relaxation of performance targets during the pilot had been realistic. However, there was some feeling that staff had been left to find their way through problems by those who designed the pilot. It could have been helpful to have some 'project support'; for example, some meetings with staff in other offices, or project personnel who kept closely in touch with what was happening, and were available to discuss issues as they arose, especially in the early stages which were hard.

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<sup>10</sup> Delayed decisions do not automatically mean delayed benefit payments, as people receive benefit while waiting for a Personal Capability Assessment decision.

Looking back on the pilot, the main weaknesses perceived were:

- the lack of IT support, increasing clerical and manual workload;
- introduction of changes during the pilot, requiring re-learning and leading to some confusion;
- lack of overall support and information for staff running a pilot.

Requirements for both GP and claimant consent were not seen as weaknesses, but as factors which increased complexity, created extra administration and, in some cases, delays.

When asked about the strengths of the pilot arrangements, one view was that claimants would have no grounds for believing that their case had not been looked at thoroughly. There would be less chance of doctors conducting medical examinations without relevant information. This might lead to fewer telephone calls from angry claimants. There was some doubt that there would be much effect on the number of appeals, however, as many factors influenced whether people appealed against withdrawal of benefit.

On balance, it was thought better to have run a pilot than not, when considering a major change in procedure. An additional strength of the pilot was that there were now administrative staff who had key information and expertise if decisions were taken to introduce the new arrangements generally. Staff hoped that they would be consulted. They felt their views would be of great value, for example in providing advice on how to adapt the computer programme and how staff could be helped to learn the new process.

In all offices, the general view from Decision Makers was that the quality and detail of medical information extracted from GP notes and records, as seen in the case papers they were processing under the pilot arrangements, was higher in comparison with what was written on IB113 forms. If all GPs were required to cooperate; and if all claims were dealt with under these arrangements; and if there was requisite IT support staff thought medical assessments would be better. There remained some concern about whether all claimants would understand how their GP records were being used, and whether they would all agree with this. Running parallel processes, for claimants who did and did not agree to take part, would be far from ideal, however, and possibly unworkable.

## 4.2 Implementation in the Leeds Medical Services Centre

Within the Leeds Medical Services Centre administrative staff dealt with claims processed under the pilot arrangements and the usual arrangements. The team leader who oversaw this administrative work was interviewed about the impact of the pilot on the team's work, and approved doctors were also asked for their views on the workings of the pilot.

The Leeds Medical Services Centre is managed by SchlumbergerSema, a commercial company that, since 1998, has been contracted to provide the DWP and Jobcentre Plus with medical advice on state benefit claims.

### 4.2.1 Impact on working practices

The medical evidence pilot required a number of new administrative procedures to be introduced. Cases to be decided under the pilot arrangements were received from two of the participating Jobcentre Plus offices. These contained evidence that the claimant had consented to take part in the pilot. The case was first logged on a database specially created for the pilot. The database was used to track the progress of the case and to record information intended to assist SchlumbergerSema and

DWP in the evaluation of the pilot. The next task within the Medical Services Centre was to request the GP notes. This required a notification to be sent to the courier firm, which included the claimant's consent.

The task of the courier firm was to arrange collection of the claimant's record from the GP's surgery, scan the contents onto a CD, and deliver this to the Medical Services Centre. The target for achieving this turnaround of cases was set at ten days. It was reported that in most cases this target was met. Security of the CD was important. Deliveries from the courier firm were made directly to a secure, locked office to which access was restricted. In the Medical Services Centre the CD was then linked to the appropriate paper case file and allocated to one of the approved doctors, who took whatever action was required (i.e. made a decision about exemption, or carried out a scrutiny of the case).

These administrative procedures contrast with the usual arrangements for dealing with incapacity benefit claims. Here case files arrived from a Jobcentre Plus office and were allocated immediately to an approved doctor. Staff in the Jobcentre Plus office may already have requested an IB113 from the claimant's GP on behalf of the medical officer. If an IB113 report had been returned it was in the claimant's file. Under the pilot arrangements, therefore, there was an additional stage in the administration of claims, and one of the impacts of the pilot was that the time a case spent in the Medical Services Centre had increased in comparison with the usual arrangements.

Under the usual arrangements an approved doctor requiring further information from a GP about a claim had two main options. They could pass the case back to the administrative staff with instructions to send the GP an IB113 or they could complete a customised 'request for information' form (FRP2) containing specific questions about the claimant. The first of these options was rendered unnecessary under the pilot because all cases contained an SB2 form in place of the IB113. In principle, therefore, the pilot could be expected to produce a reduction in this kind of work for administrative staff. In practice, few such additional requests for IB113s are ever made and no actual reduction had been noticed.

It was reported that the flow of pilot cases had been very slow in the early months and had increased only gradually. At its peak, however, the flow had reached around 20 cases per day. By the time of the research interviews towards the end of the pilot, the rate had fallen to around four a day.

It was explained that as soon as a CD of a claimant's GP record had arrived in the Centre it was allocated to an approved doctor for action. Cases were not stockpiled until a predetermined number had been reached, nor were different types of case allocated to particular doctors. The aim was to process the claims as quickly as possible in order to meet internal targets and contractual requirements.

It was noted that the task of collecting and entering information about processing claims for monitoring and evaluation purposes had been an additional impact of the pilot. However, it was recognised that this work was linked to the design of the pilot and would not continue in the same form after its end.

#### **4.2.2 Implications of the pilot**

The pilot was reported to have created additional work for the administrative staff of the Leeds Medical Services Centre. This work was not in itself problematic. The systems that had been put in place to administer and monitor the pilot had worked well. In conjunction with the courier firm the supply and secure handling of the CDs of GP records had also worked well.

If the pilot was to be extended elsewhere, it was suggested that consideration could usefully be given to two particular aspects of the pilot arrangements. First, the additional work placed on Medical Services Centres in arranging collection of GP records and in handling them securely would have resource implications if this task remained with them in the future. Secondly, there was a perception that the requirement to send copies of claimants' consents to the courier firm added to the administrative burden in processing cases. There was, therefore, the potential of reducing this by designing different consent procedures based, perhaps, on some form of electronic transfer.

### 4.3 Summary

The pilot created extra administrative and clerical work for Jobcentre processing staff and the Medical Services Centre. The staff involved were interested in the project and committed to implementing the pilot arrangements efficiently. These staff have key information and expertise if decisions are taken to develop the new arrangements at a national level.

## 5 Using GP records in the administration of Incapacity Benefit

This chapter presents the experiences and views of approved doctors about the pilot arrangements and their usual methods for processing incapacity benefit claims. Approved doctors play a central part in both the use and production of medical information, and under the pilot arrangements are the only people to make direct use of the actual GP records supplied by the practice. The next chapter explores the use of medical information by Examining Medical Officers (EMOs) and by Jobcentre Plus decision makers.

For Incapacity Benefit claims, the role of the approved doctor encompasses the following:

- to advise a decision maker whether a claimant's medical condition or disability appears to meet the criteria for exemption from the Personal Capability Assessment (PCA);
- to advise a decision maker about a claimant's functional status in relation to the PCA on the paper evidence (the 'scrutiny' stage); and
- where required, to advise a decision maker about a claimant's functional status in relation to the PCA, following a face to face examination (the PCA examination).

Under the pilot, the approved doctor had the additional task of extracting relevant data from GP records to prepare an SB2 form (extract of GP records).

The SB2 information is subsequently used by an approved doctor as medical evidence to inform one or more of the above three advisory stages of the PCA process.

At the time of the research interviews, four approved doctors were carrying out these tasks. Two of these doctors also had experience of carrying out medical examinations for incapacity benefit claimants. All four approved doctors were interviewed for the research. Full details of the conduct of the interviews are in Appendix A.

Section 5.1 presents findings on the experience of the exemption stage of the process. Section 5.2 presents findings on the process of extracting information from GP records and views on the quality of GP records that approved doctors work with. Experiences of the scrutiny stage of the process are discussed in Section 5.3. The last part of this chapter presents the overall views of approved doctors about the pilot arrangements.



## 5.1 Extracting information from GP records

The process of extracting data that approved doctors are expected to follow was defined under the administrative rules drawn up for the pilot. Only information relevant to the incapacity benefit claim should have been extracted. Extracts were copied directly from the scanned GP records. These might include the handwritten or computer notes made by the GP or other practice staff, prescription records, hospital letters or investigation reports (such as x-ray or pathology), and reports from other professionals. Approved doctors were permitted to transcribe handwriting and could add their own commentary to the SB2 form drawing attention to particular aspects of the information. In the interviews, approved doctors referred to two main types of comment. The first would draw the attention of any subsequent EMO to one or more of the extracts that they should specifically refer to when they prepared their report of the medical examination (on form IB85). The second would note relevant gaps in the GP record, for example, when the claimant's IB50 reported a condition of which there was no mention in the GP record.

Two aspects of extracting information from GP records drew adverse comments from approved doctors. First, the requirement under the pilot rules to identify and extract the earliest and most recent consultation dates in relation to the claimant's relevant health condition was felt to be time consuming, particularly when the maximum of five years' records had to be examined. It could also be of very little use in cases where, for example, a decision to exempt might rely on the presence of a medical condition at the time of the claim, rather than when that condition was first diagnosed. A second criticism was that in many cases, particularly first claims, it was necessary to extract recent information. Experience had shown that in relatively few cases was there any relevant, useful information from more than two years back. Time spent trawling back five years in all cases was, therefore, unnecessary and unproductive.

The process of extracting information from GP records was a varied experience. It could be relatively easy and quick or long and laborious depending on the medical history of the claimant and the volume and quality of the GP records. (The quality of GP records is discussed in the following section.) During the course of the pilot there had been improvements in the computer software used for extracting information that had been welcome, and had reduced the time needed for the task.

Approved doctors interviewed were asked to describe how they approached the task of extracting information from GP records. Two, almost conflicting, approaches emerged. On the one hand, there was a view that only information relevant to what the claimant had recorded on their claim as their relevant health condition(s) should be extracted. The more common view, however, was that any medical information that could have a bearing on a person's functionality in relation to the IB medical assessment process should be extracted. This was based on the view that claimants are not necessarily competent to know the extent to which their various conditions (especially in combination) affect their functionality. One approved doctor explained that he wanted to prevent a situation where an EMO was faced with a claimant describing things in the examination to which there was no reference in the SB2. This would lead to unnecessary confusion and doubt.

Discussions with approved doctors about using GP records also showed that the amount and type of information extracted by some doctors had changed over the course of the pilot. At the start of the pilot, the common practice was principally to extract information that gave the '*story of the claimant's condition*' as comprehensively as possible (over the past five years). The length of the SB2 extracts varied accordingly. As the pilot progressed (and at the time of the research interviews) a variation in this approach was reported, in which greater emphasis was placed on information having a possible bearing on assessing functionality. Information giving the '*story*' was deliberately limited, for

example, to the previous 12 months (unless there was important information from earlier). However, information about functionality was rarely expressed explicitly in GP records and therefore approved doctors looked for indirect or implicit information (referred to as '*clues*' and '*hints*' by one). An example given was a reference in a claimant's records to a recent flight abroad, which might be an indication of the claimant's ability to sit for extended periods. A reference in a GP record to recent decorating might indicate the extent to which a claimant could stand or stretch. Approved doctors were therefore tending to include as much of this type of information in their extracts in order to indicate to EMOs aspects of the claimant's condition that could usefully be explored in the medical examination.

### 5.1.1 Content and standards of GP records

The point was made consistently that GP records are kept primarily to enable the GP to record their clinical findings and diagnosis and to track the treatment of their patient; they are not geared towards assessing disability and functionality. It was rare, for example, for GP records to contain information about the distances a person could walk. One approved doctor described this as a '*fundamental flaw*' in the use of GP case notes as a source of evidence for incapacity benefit assessments.

Another consistent point was that GP records varied enormously in quality (in both content and methods used for recording). Principal problems with GP records reported by approved doctors included legibility and content.

It was estimated that the percentage of handwritten notes that were illegible was between 40 and 60 per cent. Computerised notes were always legible but not necessarily more useful than handwritten notes. It had been noted that some GPs tended to write very short entries on computer compared with previous handwritten notes, which tended to be fuller. It was suggested that this may be related to GPs' age and their familiarity with using computers. Younger GPs were thought to write more than older GPs. This pattern was expected to change as GPs generally became more experienced in using computers.

Variations in the amount of information recorded by GPs in their notes also drew some criticism. In reaching this view approved doctors were drawing on perceived standards of good clinical practice. It was recognised and accepted that often GP records did not actually need to record much information, and that in busy practices there was always pressure to write notes quickly. An example was given of a stable patient whose condition required only repeat prescriptions but not face-to-face consultations. The record of such a patient was likely to be thin and of little help for benefit purposes. Nevertheless, while approved doctors described some GP records as containing a depth of information that allowed them to get a full and rounded picture of the claimant's condition and its effects, they also found that some GPs' notes clearly did not.

A separate concern was that information relevant to the claimant's health might not be contained (at least in any detail) in GP records. Sometimes, for example, a claimant might have extensive contact with health professionals other than their GP (such as community psychiatric nurses, drug rehabilitation workers, or alternative therapists) but there might be little information about these contacts in the records.

Approved doctors reported that they did not often follow up with the GP gaps in the claimant's medical history. There was a shared recognition and understanding that GPs' working lives were extremely busy and that requests for further information would generally be unwelcome. One exception to this approach was reported, however. If there was a possibility of exempting a claimant (particularly a patient with a potentially severe mental health condition) then more information might be sought in order to prevent the claimant from going through a possibly stressful assessment

process. In such cases, approved doctors used the standard form (FRR2) that allowed specific questions about the claimant to be put to the GP. This sort of approach elicited responses in around half to two-thirds of cases. It was not common practice to ask GPs for further information where their notes were illegible.

## 5.2 Using GP records at the exemption stage

As explained in Chapter 1, people with severe health conditions are exempt from the PCA. Staff in Jobcentre Plus offices are able to make exemption decisions without the need for advice from an approved doctor where it is apparent from information already held that such a condition exists, for example, where a person is receiving the highest rate care component of Disability Living Allowance. Where it appears that the claimant may have a severe condition which would exempt them, the decision maker will request the advice of an approved doctor and factual clinical information will be sought from the claimant's own doctor, usually the GP. Such cases are treated as 'potentially exempt'. An approved doctor will consider the evidence, including any report from the claimant's own doctor, and then advise the decision maker if the claimant's medical condition falls within one of the exempt categories defined in legislation.

For the duration of the pilot, approved doctors had information from the claimant's case file plus either an SB2 extract of the scanned GP records (pilot cases), or an IB113 form completed by the claimant's own doctor (non-pilot cases). In addition, for re-referral PCA cases, the claimant's Incapacity Benefit casefile contained documentation relevant to previous periods of payment, including earlier medical assessment and reports.

Approved doctors interviewed described the process of advising whether a claimant's condition fell into an exempt category as relatively straightforward. The exemption categories are defined in Regulations and information about a claimant's diagnosis and treatment was particularly useful to the approved doctor. This is clinical information; at this stage the effect of the claimant's condition on functionality was not as relevant as later stages of the PCA process.

Approved doctors reported that sufficient, relevant information was usually easily found in either the GP's records or on the IB113. However, the GP records were generally thought to contain more information than most IB113s and to give a more complete picture of the claimant's clinical condition. For some re-referral cases it was found that the picture of the claimant that emerged from GP records differed from the picture presented in the IB113 reports for previous claims. Typically in such cases the claimant's condition appeared much less severe from a reading of the GP records compared with the picture presented in earlier IB113s or other medical reports. Approved doctors reflected on this finding and speculated that had such cases not been part of the pilot it was likely that a misleading picture of the claimant would have been perpetuated in a new IB113 (and leading possibly to incorrect advice on exemption).

A possible explanation for this was suggested. It was felt that what the GP wrote on any medical form relating to benefits was influenced by their relationship with the patient. It was thought common practice for GPs to describe patients' conditions in such a way as to reflect, and not to challenge, how they presented themselves to the doctor and to ease relations with an employer. For example, while a Med4 form might give a diagnosis of 'depression' there could be nothing in the GP records that was evidence of a clinical condition. It might be more likely that the patient was unhappy in some aspects of their life, which might, in the GP's view, improve with a period of time away from work. Thus recording 'depression' on the Med4 would make dealings with an employer less problematic. The problem for benefit purposes was that such diagnoses could find themselves repeated on IB113 forms.

A positive effect of the pilot arrangements was that GP records often allowed approved doctors to form a view about the severity of a condition, and therefore whether exemption could be advised, in cases where a simple diagnosis would not allow this. An example cited here was where a diagnosis of 'depression' appeared on an IB1 13 without further elaboration from the GP. From this information alone an approved doctor would not be able to assess whether the claimant was suffering from a 'severe mental illness'. In such a case, the claimant would be asked to complete an IB50 in the usual way. However, a GP record might provide additional information that would allow a decision to exempt to be made. A similar example, but leading to a different outcome, was where schizophrenia is given on an IB1 13 as the primary diagnosis. Under the usual arrangements, such a diagnosis would be likely to lead to advice to the decision maker to exempt the claimant. This was described by an approved doctor as giving the claimant *'the benefit of the doubt'*. However, GP records showing that a patient's schizophrenia was well controlled and that the patient was living in a stable environment, for example, might suggest that 'severe mental illness' was not present and that exemption was not justified.

Based on their experiences of the pilot at the time of interview, approved doctors reported an increased level of confidence in their advice to decision makers about whether to exempt, or not exempt, which derived from the fuller information available from the claimant's GP record. However, this increased confidence should not be overstated; approved doctors were already generally confident in the correctness of advice based on the information in IB1 13 forms.

It was hard for approved doctors to assess whether they were advising more exemptions under the pilot. This was partly because so few cases appeared eligible for exemption under the usual arrangements, making it difficult to identify a change. It was also partly because the effect on advice of using GP records was not perceived as only in one direction. As described above, the additional information in GP records could lead equally to advice to exempt or advice not to exempt depending on the nature of the information.

The process of providing advice about exemption was thought to take slightly longer under the pilot arrangements, because it was necessary to examine the GP records to identify the appropriate diagnosis. In contrast, a diagnosis was usually quick and easy to find on an IB1 13.

In summary, approved doctors expressed a preference for using the SB2 extract of the GP records to provide advice about exemption. IB1 13 forms were satisfactory for the purpose in most cases but they varied in quality. GP records were more consistently useful in comparison. However, the impact on the substance of the advice provided was thought to be marginal.

### 5.3 Using the SB2 extract of the GP records at the PCA scrutiny stage

At the 'scrutiny stage' of the incapacity benefit PCA process, approved doctors are required to advise a decision maker as to whether a claim can be accepted without a medical examination of the claimant or whether an examination is necessary.

To provide this advice, approved doctors examine all the evidence before them. For pilot cases, this included a completed SB2 form with extracts from the GP record. For other cases, there may have been an IB1 13 report or a Med 4 form from the claimant's GP.

One of the planned outcomes of the pilot was a reduction in the number of cases sent for examination after scrutiny. It was expected that the information available from GP records would enable approved doctors to advise on more claims without an examination than under the usual (non-pilot)

arrangements. The experience reported by approved doctors was the opposite however. In their view, there had been an increase in the proportion of cases scrutinised and then called for examination. The additional evidence available in pilot cases was thought to have provided information which raised doubts in the minds of the approved doctors about whether the claimant's score reached the appropriate threshold of 10 or 15 points. This was particularly the case in relation to re-referral cases. Several contributory reasons were suggested:

- Because of the **amount** of information. There was more information in the records that was relevant or up to date. On re-referral cases in particular, advice under the usual arrangements was sometimes made, relying on information from older claims. If there was no evidence that anything had changed, then an assumption was often made (in the claimant's favour) that nothing had actually changed in practice and the claim was passed. The pilot had shown that some of these assumptions were probably unjustified
- Because of the **scope and extent** of the information. There was a feeling that some GPs presented only a partial picture of their patient on an IB113 which would count in their favour for benefit purposes. In contrast, GP records might show (for example in hospital reports) degrees of improvement not reported on the IB113.
- Because of the **accuracy** of the information. The diagnoses recorded on the IB113s or Med3s and Med4s were sometimes not borne out by the GP records.

In contrast, approved doctors also reported that there had been cases where the information from the GP records had allowed them either to advise exemption or to advise on cases at the scrutiny stage, that under the usual arrangements where IB113 information was available would be sent for examination.

In comparing the relative merits of SB2s and IB113s, approved doctors reported that using information from the GP records allowed them to provide '*stronger*', better justified advice to the decision maker. There was agreement however, that when IB113s were completed well by GPs, their advice was equally good. Medical information was not intrinsically '*better*' in SB2s compared with IB113s, but it was different. Fuller clinical information was generated in the pilot, but a good IB113 would contain more information about the effects of the patient's condition. Both systems could work well, therefore, but both were reliant on good information from the GP whether directly from the records in the case of the pilot or from an IB113 in the cases of the usual arrangements. Whether an IB113 was completed by the GP or a member of the practice staff was not a major issue with approved doctors. It was recognised that it was usual practice in some surgeries for practice staff to fill in parts or all of the IB113 form<sup>11</sup>, and experience had demonstrated that some forms completed by, for example, practice nurses, were as useful or better, than some completed by GPs.

## 5.4 Overall views of approved doctors

Approved doctors in Leeds expressed an overall preference for an advisory system based on information from GP records rather than the existing system that relied on GPs completing an IB113 form.

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<sup>11</sup> Notwithstanding which individual within a GP practice writes information on the IB113 the GP has overall responsibility in all cases for providing medical information to the approved doctor.

The advantages were summarised as follows:

- GP records could potentially be collected on all cases; at present only a proportion of IB113s were returned by GPs.
- Although GP records varied in quality, many compared favourably with the quality of IB113s.
- GP records could contain fuller, more accurate, more objective and more up-to-date clinical information than many IB113s.

It was felt that GP records were particularly useful for re-referral cases where there was often little up-to-date information supplied on an IB113. They were also useful for claims from people with mental health conditions because the diagnosis on an IB113 was often insufficient to allow them to advise about exemption.

Criticisms of the pilot arrangements included the following:

- Administrative rules set up for the pilot were too rigid. Information relating to first and most recent consultations, and information spanning five years was not always necessary.
- GP records did not contain much direct information about functionality (compared with 'good' IB113s).

In Chapter 7 we return to the experiences of approved doctors and consider how their reflections and observations can inform thinking about the use of medical information in the future.



## 6 Using the SB2 form in the medical examination and in decision making

This chapter presents the experiences and views of approved doctors acting as examining medical officers (EMOs) and of benefit decision makers in Jobcentre Plus about the pilot arrangements and the usual methods for processing incapacity benefit claims. For pilot cases, the EMO would have had access to the SB2 (extract of relevant details from the claimant's GP records) and this form would also have been available to the benefit decision maker. At no time did the EMO or decision maker have access to the full scanned GP records.

For the purposes of this research, all six EMOs, who were carrying out regular examinations of incapacity benefit claimants under the pilot arrangements, were interviewed. Each had had specialist training on using the information contained within the SB2 forms as part of the medical examination. We also involved all ten Jobcentre Plus incapacity benefit decision makers in Sheffield and Rotherham in the research. Six were interviewed individually, and four took part in a group discussion.

Section 6.1 describes the role of EMOs in the administration of incapacity benefit and how they use medical information. Section 6.2 presents findings of the impact of the pilot arrangements on the work of EMOs and Section 6.3 compares the relative advantages and disadvantages of using SB2 and IB113 forms under the pilot and usual arrangements. Section 6.4 summarises EMOs' views of the pilot. In Section 6.5 the role of the Jobcentre Plus decision makers is explored, before presenting findings on the impact on their work of the pilot arrangements in Section 6.6. Section 6.7 compares how the SB2 and IB113 forms contribute to the decision-making process from the perspective of decision makers, and the final part of the chapter summarises their overall views of the pilot.

### 6.1 The role of Examining Medical Officers

The role of examining medical officers is to examine incapacity benefit claimants and to produce a medical report for the use of Jobcentre Plus decision makers. EMOs see only a subset of incapacity benefit claimants largely comprising those where there is insufficient evidence or where the available evidence casts doubt on their functional incapacity. Following an examination of the claimant, EMOs provide advice to the decision maker in the form of a detailed written report.



A medical examination may comprise a physical examination of the claimant and/or, where there is a mental health problem, a mental health assessment. All examinations are conducted face to face and usually take place in a designated Medical Examination Centre.

In preparing for a medical examination the EMO has access to the documentation held by DWP relating to the claimant. There may be considerable information about claimants with a long history of claiming Incapacity Benefit, or relatively less for new claimants. For pilot cases, the information included an SB2 form. For non-pilot cases there may or may not be an IB113 medical report or a Med 4 statement from the certifying medical practitioner, usually the claimant's GP. EMOs explained that they used the information available to identify particular aspects of the claimant's medical history or functionality that they would need to explore in the medical examination.

EMOs all said that they routinely explained in general terms at the start of the face-to-face examination with the claimant that medical information had been collected from GPs, hospitals and others. Some claimants were reported to be particularly concerned to know that a full history of their condition was contained in their case file and wanted reassurance that the EMO was knowledgeable about their condition. However, EMOs were clear that they did not refer to specific pieces of medical information or their source during the examination. No EMO had mentioned to a claimant that they had extracts from GP records. It was explained that there was a risk of damaging the relationship between GP and patient if the latter inferred at a later date that information from their GP had led to a disallowance. EMOs were acutely aware that relationships between GPs and patients were sometimes fragile or vulnerable.

The role of the EMO after the examination is to complete a medical report form, IB85. This form contains the same set of descriptors as the IB50 completed by the claimant. EMOs must advise the decision maker with a choice of descriptor in each of the functional categories and must justify that choice with medical evidence and reasoning. Under the pilot arrangements EMOs were required to make a reference at the appropriate place on the IB85 to any relevant information in the SB2 form.

## 6.2 The impact of the pilot arrangements for Examining Medical Officers

There was a general consensus among EMOs that the pilot arrangements had little impact on the process of examining claimants and on the choice of descriptors they made. There was less consensus on the impact of the pilot on the content and depth of their medical reports.

There was some surprise at the lack of impact on medical examinations. Some EMOs had looked forward to having, at hand, detailed clinical information in the SB2 forms. When EMOs were asked to reflect on the perceived lack of impact, several possible explanations emerged. It was noted that the job of the EMO was to make judgments about functionality, but information about functionality was rarely contained in SB2 extracts. In order to make choices of descriptors they relied far more on what they found at examination, where they were able to make direct observations about functionality, or ask questions about functionality of claimants with mental health conditions. One EMO commented that the amount of time spent with a claimant was substantial (around 30 minutes was common), particularly in comparison with the average GP consultation time. A considerable amount of relevant information could be collected in this time and was usually the main influence on the choice of descriptors.

No EMO said that extracts from GP records hindered them in the job of examining, and most expressed some level of interest or approval. Some liked the fuller medical histories that were contained in SB2s, but it was not common that the additional information available had much effect

on individual cases. For one EMO, this was both disappointing and reassuring. It was thought beforehand that information like hospital reports, or results from x-ray or pathology tests, would have an important positive effect on the types of decisions EMOs made, but this was not the experience. This was disappointing. However, it was also reassuring to know that in the absence of such information in the past decisions about descriptors were as good.

Although EMOs felt there was no apparent effect on their choice of descriptors, it was reported by some that decisions about re-referral dates had been influenced by information from GP records. For example, the record may contain firm dates of forthcoming operations or other relevant procedures. One EMO commented that in a few cases it was possible to set a longer re-referral date because of the fuller information in the SB2. (In the absence of such clinical information it would be usual practice to set a shorter re-referral date.)

One anticipated impact of the pilot was that EMOs would see fewer claimants who, in their assessment, were eligible for exemption because these would have been identified earlier in the process by an approved doctor scrutinising the paper evidence, including the extract from the GP record. However, it was hard for EMOs to make an assessment about whether they were making fewer decisions to exempt at the medical examination stage. This was partly because EMOs were still seeing many non-pilot cases as well as pilot cases throughout 2002 and distinguishing between the two types at the time of the research interview was not easy. One EMO mentioned that the most recent cases, where exemption had been advised following an examination, were non-pilot cases.

EMOs all commented that the pilot arrangements had affected the way in which they completed IB85 medical reports. They all reported spending more time on the reports because of the requirement to make reference to the SB2 in the justifications for descriptors. Some said that they felt their advice was better justified and as a result had an increased level of confidence in their correctness. Others did not feel able to offer an assessment here, but none said there had been an adverse effect on their reports.

## 6.3 Examining Medical Officers' experiences of using SB2 and IB113 forms

EMOs were asked to reflect on the ease of use of SB2 forms in comparison with IB113 forms in use on non-pilot cases. Comments covered a number of different aspects.

### 6.3.1 Information about functionality

It was generally acknowledged that GP records were not a good source of information about functionality. One EMO, however, did not share that view, suggesting that clinical information could yield strong indications about a person's likely functionality. (An example was given where an SB2 might refer to a recent leg injury or operation from which some idea about the claimant's ability to walk could be inferred.) It was felt that the IB113 had the greater potential for generating information about functionality because the wording of the form gave the opportunity to GPs to provide such information. In practice, however, many IB113 forms contained little or no such information.

### 6.3.2 Objectivity of medical information

It was felt by some EMOs that the information extracted from GP records was likely to be factual and objective. In contrast there was a feeling that some IB113 forms were completed by GPs in a more subjective manner, presenting information in such a way as to promote their patient's claim for benefit. (Comparing this view with the evidence from GPs presented in Chapter 2, it seems that this feeling would be justified in some cases.)

SB2 forms were also felt to contribute to objectivity in a different way. It was observed by some EMOs that the picture of a claimant's health that emerged from the GP's own notes sometimes differed from that emerging from hospital and other records. One possible explanation for this was felt to be the possibility that some people present themselves in different ways depending on their perception of the purpose of the interaction. The way patients talk about themselves to a GP, from whom they might want a medical certificate, may thus be different from the way they talk to hospital staff, from whom they are seeking treatment. The information in SB2 forms from external sources was therefore thought to act as a useful check on the validity of the information recorded in GP case notes.

### 6.3.3 Appropriate period for extracting medical information

This was an issue relating to the pilot only. As explained in Chapter 1, five years was chosen as the time period for which approved doctors would extract information from GP records in the pilot. There is no comparable time limit imposed on GPs completing IB113s, who are free to present information going back as far as they see fit.

There were mixed views about whether five years worth of medical information was useful to EMOs. The dominant view was that in assessing functionality only more recent information was necessary, perhaps over the past two years (possibly three years). It was rare that information going back five years was needed. A different view was that five years' information was often useful in gaining a good understanding about the claimant's current health status, and that it would be preferable to maintain this period if the pilot arrangements were adopted in the future.

### 6.3.4 Gaps in information

There was general agreement that neither the pilot nor the usual arrangements were designed to generate information directly from other health professionals, such as mental health teams, rehabilitation workers or carers. However, there were differing views about whether this was an important omission. One view was that such information would be valuable and likely to be more relevant to functionality than factual clinical data. This would be particularly useful when the treatment of a patient did not require them to have direct contact with their GP. A counter view was that information from psychiatric or other support workers was likely to be couched in terms favourable to the claimant, and hence, too subjective to be useful. One EMO was able to draw on previous experience of working as a tribunal member to support this with a view that information provided at tribunal hearings by support workers was often more hindrance than assistance.

### 6.3.5 Understanding the claimant's medical history

One, minor, criticism of the SB2 reporting arrangements was that it was sometimes necessary to piece together the claimant's medical history from the chronological extracts in the SB2. This was more of a chore when the claimant had multiple health conditions. In comparison, the IB113 was much easier to read and understand because the GP usually gave a coherent summary of the claimant's health.

### 6.3.6 Legibility

Legibility of GPs' handwriting was an issue for both SB2s and IB113s. It was welcome that many GP records were computerised, and copies of hospital letters were always legible. There was some criticism that hard-to-read extracts were not always transcribed by the approved doctors in Leeds.

## 6.4 Examining Medical Officers' overall views of the pilot

EMOs were asked if they had a preference for working with the pilot arrangements or the usual arrangements. No clear view emerged. There were supporters of each whilst some preferred to reserve their judgment.

Preferences for the pilot arrangements were based on the following reasons:

- A system where *some* information was almost guaranteed was preferable to the current arrangements when many cases had no IB113s, and many of those returned were of very limited, or no, use.
- The information in SB2s gave a more complete clinical picture of the claimant.
- SB2s were considered more objective than IB113s.

Disadvantages with the pilot arrangements included:

- the additional time required to deal with cases; estimated at between five and ten minutes per case (in order to read and assimilate the information and to write more detailed IB85 reports);
- lack of direct information about functionality.

The main advantage of the usual arrangements was that IB113 forms contained questions specifically designed to elicit relevant, useful information about functionality.

The final observation from EMOs was that what they required was high quality information. Whether this came via an IB113 or in extracts from GP records was less of an issue. IB113s could be excellent, and equally when a GP's original records were poor, an SB2 could be of little use. Some EMOs thought that variety in GP responses to IB113s would always exist, and hence an alternative system was preferable. Others had suggestions for building on and improving the current arrangements. We return to these in Chapter 7.

## 6.5 The role of Jobcentre Plus decision makers

Jobcentre Plus decision makers have a specialist role within the administration of incapacity benefit. Most of their work is concerned with deciding cases in which a Personal Capability Assessment (PCA) has been required but the advice from the EMO indicates that the claimant has not met the PCA criteria at the medical examination stage. There are two main types of case, therefore, that come before them for consideration. First, cases in which the claimant's IB50 has been scored at less than the threshold level and the EMO has similarly scored them at less than the threshold. Decision makers described these cases as straightforward and easy to decide as disallowances because there was no conflict of evidence. The second type of case was where the IB50 score differed from the EMO's assessment, i.e. there was a conflict between the choice of descriptors by the claimant and EMO.

Information provided by certifying medical practitioners (on an IB113 form, a Med 4 statement or via an SB2 extract of GP notes) is primarily for the use of the approved doctor (a DWP medical officer). Such evidence is used by the approved doctor to provide advice to the benefit decision maker. However, once used by the approved doctor, this evidence also becomes part of the claimant's incapacity benefit case file and is available to, and may be used by, the benefit decision maker.

Decision makers reported that in cases where the EMO scored the claimant above the threshold but the claimant's IB50 was scored below, it was usual that the assessment of the EMO would prevail and an award of incapacity benefit would be made. In contrast, cases where the IB50 had been scored

above the threshold but the EMO report gave a score lower, caused decision makers the most difficulty. The task for decision makers here was essentially to decide between one or more competing PCA descriptors.

Decision makers described the usual process of dealing with this type of case, for which they had access to all the material contained in the claimant's case file, including claim forms and medical reports from previous claims. Decision makers first looked at the choice of descriptor and any supporting information from the claimant on the IB50 and from the EMO on the IB85 medical report form. It was clear, from the decision makers, that these two documents were the principal sources used. If there was information from the GP available (in an SB2 for pilot cases, and an IB1 13 for other cases) then this would also be examined to identify anything that would support either the claimant's or the EMO's choice of descriptors.

Decision makers described their task as being reliant on good quality information. One of the aims of the pilot arrangements was to improve quality of information in the expectation that the quality of decisions on incapacity benefit claims would improve as a result. The next section presents findings on the impact on the pilot arrangements on these two aspects of quality.

## 6.6 The impact of the pilot arrangements for decision makers

There was a general consensus that the pilot arrangements had had little impact either on the quality of IB85 medical reports produced by EMOs or on the substance or quality of decision makers' own decisions. Both these experiences were reported by decision makers with a degree of surprise and disappointment. There had been an expectation of a much greater and more beneficial effect from having access to information from GP records.

Decision makers reported that changes in the quality of IB85s were not easy to identify because there was already a variation in the type and amount of information provided by different EMOs. During the period of the pilot these variations persisted.

There was some recognition that in IB85s for pilot cases, the choice of descriptors was almost always accompanied by some form of justification that referred to the SB2. In itself this was useful in demonstrating to decision makers that EMOs had actually consulted the SB2. However, what was written in the IB85 as justification was not always useful. One decision maker reported that references such as 'no relevant information on SB2' or 'I have taken into account the contents of the SB2' did not help them understand how the SB2 information (or lack of information) influenced their decision.

All the decision makers interviewed said that they had not noticed any effect on their decisions from the pilot arrangements. However, some decision makers who had seen relatively few cases, found it hard to offer an informed assessment here. In contrast, some were definite in the view that the pilot had had no effect, saying that they thought their decisions would have been exactly the same under the usual arrangements. It was also difficult for decision makers to judge whether they had more confidence in pilot case decisions. Any information that supported their decisions was useful. This came from SB2s in some cases and from IB1 13s and other sources in other cases. There was no feeling that the pilot arrangements had particularly increased their confidence in decisions.

## 6.7 Decision makers' experiences of using SB2 and IB113 forms

Decision makers were asked to reflect on their experience of using SB2 forms in comparison with using IB113s on non-pilot cases. Comments covered a number of different aspects.

### 6.7.1 Relevance of information

All the decision makers interviewed had views about the type of information extracted from GP records and presented in SB2 reports. There was a common understanding that the information was intended primarily for the use of approved doctors, including EMOs, and not for them. They found it difficult to interpret and understand some of the clinical information, much of which contained technical terms and expressions. Diagrams drawn by GPs in their notes were particularly difficult to understand. They felt unable to use much of the information in the SB2, therefore, and reluctant to make guesses or assumptions in case they made mistakes. In contrast, information that related to the claimant's functionality was welcome and easier to understand and use. There was a feeling that IB113s were generally better at providing such information when they were completed well by GPs. They were also less likely to contain technical jargon. However, there was the recognition that many GPs failed to return IB113s and that of those that were filled in, probably many were of little or no use because of the paucity of information provided.<sup>12</sup>

It was recognised that IB113s were filled in by non-GP staff in some practices. There was no strong feeling about the acceptability of this and it was noted that forms completed by nursing staff were often better than many filled in by GPs.

Decision makers described a range of resources they could use when they were unsure about some aspect of a case. These included the knowledge and experience of their colleagues, guidance and reference materials (such as Black's Medical Dictionary), and the knowledge of approved doctors (in the Leeds Medical Services Centre or in local Medical Examination Centres). Decision makers tended not to consult approved doctors very often, but they had proved useful in explaining medical conditions and terms that occurred only rarely. GPs and claimants were not consulted for further information.

### 6.7.2 Legibility

Legibility of handwriting was a source of serious concern and frustration for decision makers. It was impossible to make use of illegible information in SB2s or IB113s. There was again some surprise and disappointment that illegible extracts from GP records were not always transcribed by approved doctors. The point was made that if an extract had been selected then presumably a doctor had been able to read it at some stage. That few transcriptions appeared in SB2s reinforced the perception that they were intended for the use of approved doctors, including EMOs, primarily.

There was also concern that some handwritten IB85s were difficult to read. However, in such cases, the decision maker could send the case back to the relevant EMO or consult them directly. This was an irritation to decision makers and EMOs and slowed down the progress of the case.<sup>13</sup>

<sup>12</sup> One of the reasons why cases are referred for examination is a lack of medical information, which is often the result of poorly-completed IB113s. It is likely, therefore, that of the IB113s seen by decision makers, a relatively high proportion will contain little useful information. Another reason for little medical evidence being available for many cases is the IB113s are only sought in about a third of cases.

<sup>13</sup> As explained in Chapter 1, a concurrent pilot was exploring EMOs' use of a computer based system for completing IB85 reports. Towards the end of the fieldwork period, this pilot was being extended to other areas including Sheffield and Rotherham.

### 6.7.3 Confidence and trust

Several decision makers reflected on an aspect of their work that had been affected by the pilot arrangements. They commented that, in all cases, pilot and non-pilot, they needed confidence and trust in the material they had to work with. In using SB2s it appeared to them that extracts were often taken from longer reports or letters. Sometimes extracts ended in mid-sentence. Although it was recognised that an approved doctor might intentionally extract only part of a sentence, it was hard for decision makers to be certain. Doubts could therefore arise as to whether something had been missed and cause a reduction in confidence about decision making.

A different concern was raised in relation to IB85 reports. Here the issue was the use by some EMOs of the same phrases and forms of words in reports for different claimants. What decision makers preferred was an explanation in the IB85 that linked information about the claimant's condition in either the SB2 or IB113, and findings in the medical examination to the EMO's choice of descriptor. The effect of using the same phrases was that this link was not convincingly made and this reduced decision makers' confidence in their decisions.

## 6.8 Decision makers' overall views of the pilot

Decision makers were asked if they had a preference for working with the pilot arrangements or the usual arrangements. No strong views were expressed and no consensus emerged.

Some decision makers thought the principle of the IB113-based system was superior to the pilot arrangements even though there were well known deficiencies in how the system worked in practice. When IB113s were completed well, they presented an easy to follow summary of the claimant's medical history and information about functionality. SB2s rarely matched this level of usefulness. There was a slight preference among these respondents for thinking about ways of improving and building upon existing arrangements. Other decision makers acknowledged that it was preferable to have *some* information from GPs on all cases rather than very variable information on only a proportion.

Neither the current arrangements nor the pilot arrangements were seen as ideal templates for the future. However, decision makers were clear that medical information was essential to their task. The experience of working under both systems prompted decision makers to make a number of suggestions about how medical information could be generated in the future. Chapter 7 presents these, alongside the ideas from the other actors in the incapacity benefit decision making process.



## 7 Developing policy for the collection of medical evidence

In the first part of this chapter we bring together the views and experiences of all the actors in the administration of incapacity benefit on a number of policy issues relating to the use of medical evidence. Other issues have been prompted by the analysis of research data by the research team. In thinking about the future of Incapacity Benefit these issues will need careful consideration by policy makers in any reforms to the administrative arrangements for incapacity benefit.

Section 7.2 presents ideas and suggestions about how collection of medical evidence might be improved in the future. These fall into ideas for building on the current system based on the IB113 forms, for building on the pilot arrangements, and other, related ideas for generating useful and relevant information.

The final part of the chapter presents conclusions from the study.

### 7.1 Issues for policy

#### 7.1.1 Acceptability of using GP records

The main objection of principle among GPs and claimants not participating in the pilot, was that releasing GP records to people, including medical practitioners, working on behalf of DWP would breach the confidentiality of those records. It is possible that some GPs' objections might be overcome if they were satisfied that their patients had given informed consent to the release of their records. (We return to the issue of consent below.) However, it could be more difficult to persuade reluctant claimants, whose records might contain sensitive information about themselves or their families, about the desirability of allowing GP records to be used by DWP approved doctors and for a relevant extract to also be available to the benefit decision maker. Some expressed distrust about how information would be used, and suspected that there might be other, negative outcomes for them or other claimants. Some GPs held to their belief that the pilot arrangements were wrong in principle and remained opposed to them.



Other objections to the pilot arrangements related to the possible adverse effects of GP records leaving the practice premises. These included the unavailability of records when required, and the possibility of records getting lost, damaged, or being returned in a disorganised state. From the evidence of the participating GP practices, however, no such problems arose in the course of the pilot. Case files were collected and returned satisfactorily and within the three day target period. In addition, some practices had introduced their own back-up procedures (such as keeping copies of the patient's most recent records) to guard against any potential problems. The implication, therefore, is that it is possible to design systems for collection and return that should not interfere with the clinical work of GPs and which might reassure some claimants if they were explained to them.

### 7.1.2 Gaining informed consent

From the interviews with incapacity benefit claimants it was clear that overall there was little understanding of what and how medical information is used in determining their claims, variable recognition of explanations about the pilot arrangements contained in DWP letters or leaflets, and variable understanding and sometimes little interest in what was contained in GP records. Some GPs' suggestions that some people might not have sufficient knowledge to give informed consent would therefore seem to be well-founded.

In discussing the consent procedures for the pilot, GPs in this study mentioned that informed consent is an integral element of the design of therapeutic and drug trials that was very familiar to them and also that they were used to releasing records or providing photocopies to third parties, including solicitors and insurance companies, through the provision of the written consent of the patient. For the pilot, obtaining written consent involved the claimant being sent an information sheet and then ticking a box as part of the main declaration on one of the relevant forms if they did not want to take part.<sup>14</sup> Some GPs questioned whether, under this method of obtaining consent, people would be fully aware of what they were agreeing to. It is possible that, given the lack of understanding shown by both those who participated and those who did not participate in the trial, more robust procedures for informing clients to allow them to decide whether or not they wish to participate would need to be considered if the pilot arrangements were to be adopted more widely. Apart from its intrinsic desirability, some GPs will need to feel more confident that their patients are sufficiently aware of what they are agreeing to and might prefer a different method of gaining written consent from patients.

### 7.1.3 Effects on GP practice office staff

The pilot created a new set of administrative tasks for GP practice staff. Some managers felt that the work created by the new tasks was no more time-consuming than working under the usual arrangements. Others reported an overall increase in their workload. The assessment by practice managers and other administrative staff about how much extra work was created varied. Practices that chose the photocopying option seemed to have experienced the most additional work; those that supplied actual records seemed to experience the least. Practices that were fully or partly computerised had to print out records in addition to handling a case file and their workload varied.

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<sup>14</sup> These were forms that claimants were required to complete in full and sign as part of their declaration underpinning their claim to benefit or as part of the PCA process. The information leaflet for claimants attached to claim forms and IB50s explained that further enquiries could be made to a Jobcentre Plus office.

An assessment of the additional work imposed on GP practices will be relevant to decisions about appropriate remuneration under any future arrangements. The additional £10 honorarium per case record sent was not a major reason for GP practices' decisions to participate, although it was clearly seen as welcome. However, it is possible that if the photocopying option was available in the future then GP practices would require more than the £20 additional honorarium paid as part of the pilot, and for additional reimbursement for potentially large amounts of printout and scanned material.

As mentioned above, one influence on the impact on GP practice staff was the extent to which the practice used information technology. Among the practices visited in the course of this research there was a wide range in the use of computers. Some made little use and relied on a paper-based system of records; others were what they called 'fully computerised' and 'paperless'. There were some examples of innovative and creative thinking about how the use of computers could be extended. Of particular interest for this research was the development of software to enable extracts from GP records to be input directly onto medical report templates and other forms, and ideas about the use of email for responding to requests for medical information. Thinking about future arrangements will need to take account of the diversity in the use of information technology, and the possibilities and implications it presents.

#### 7.1.4 The role of practice managers

In collecting research data during the visits to GP practices, it became clear that practice managers have played a number of key roles during the course of the pilot. They have acted as the channel through which the invitation to participate reached GPs, they contributed influentially to decisions about participation, they made the practical arrangements within practice offices and often carried out most or all of the tasks associated with participation, and importantly they have fed back to GPs their experiences of the pilot. The last of these has been important in forming some GPs' views of the pilot, though it was clear that, at the time of the research interview, other GPs were not aware of the administrative impact of the pilot.

In thinking about the implementation of any future arrangements, therefore, the views and experiences of practice managers could be particularly useful.

#### 7.1.5 Assessing functionality

A common theme emerging from the interviews with staff within Medical Services and Jobcentre Plus was the general difficulty of assessing the functionality of claimants. A strong view emerged that information contained in GP records (and subsequently extracted on to SB2 forms) was not generally well suited to assessing the extent of a person's capability for carrying out the functions of everyday living. This is not surprising. GP records are kept for the primary purpose of recording clinical findings and to support the management of a patient's condition. From the accounts of the approved doctors in Leeds and from GPs themselves, it is clear that GP records vary widely in the amount and quality of functional information recorded.

Overall, GP records were considered generally good for arriving at a diagnosis of the claimant's health condition or conditions. They were, therefore, useful for approved doctors providing advice about exemption, but of less use for EMOs and decision makers making assessments and judgments about functionality.

In contrast, a 'good' IB113 could contain information useful to all the people in the decision making chain, because it would contain diagnostic data *and* information relating to the tasks of everyday living. The problem for approved doctors, EMOs, and decision makers, was, as we have mentioned at various points in this report, that only in a minority of cases was a 'good' IB113 available.

Some interesting observations emerged in the research interviews about assessing functionality for claimants with a diagnosis of mental illness or who had completed the mental health questions in the IB50 form. It was a common view that the effects of any particular mental health condition could vary considerably between individual people. It was therefore difficult to arrive at a view about functionality from GP records alone. The pilot arrangements were generally felt to be more useful for claimants with only physical health conditions.

### 7.1.6 Sources of relevant information

It was generally recognised that some information that would assist people at the different stages of the decision-making process was not routinely or always to be found within GP records. This concern was expressed strongly by some claimants interviewed. Examples cited earlier in this report included information from mental health professionals, rehabilitation workers or carers. There was no consensus about the practical value of such information however. Some people in the decision-making chain advocated that greater effort should be made to collect information from other professionals because it was useful in assessing functionality. Others were wary about a possible lack of objectivity among people whose professional job was to act as supporters and advocates of their clients. While factual, objective information about functionality could be useful, information presented in the form of a supportive statement or argument was of much less use.

Possible lack of objectivity in GPs' IB113 reports has already been mentioned as a concern of some respondents and used as an argument for using GP records in their place.

### 7.1.7 Appropriate period for extracting medical information

An issue for policy is the question of what is the most appropriate period of time for taking extracts from GP records. For the purposes of the pilot, a period of up to the previous five years had been selected.

There was a general feeling that it was not possible to prescribe a 'best' period. It was recognised that for some people with chronic conditions, it was desirable to have information going back several years. In some cases, possibly most, five years would be adequate. In other cases, information going back further would be appropriate. However, there was a view that, particularly for new claimants, the onset of the condition that had led to a claim for incapacity benefit was likely to have taken place only in the 12 months prior to the claim. Earlier information was unlikely to be relevant in most cases.

In discussions about appropriate time periods, the researchers noted that some GPs and claimants talked exclusively about information needed to understand the development of the relevant health condition (the medical history or 'story' as we refer to in Chapter 4). Staff involved in the decision-making process spoke more about their need for information about functionality. In their view, little could be learned in most cases about a claimant's functionality, at the point of the incapacity benefit claim from clinical data going back five years. For new claimants in particular, therefore, they would be happy to have information for a shorter period. Between 12 and 24 months was suggested as satisfactory.

### 7.1.8 The stock of incapacity benefit claims

The stock of incapacity benefit claimants have been in receipt of the benefit for varying lengths of time, some for many years. One effect of the pilot, noted by approved doctors and reported in Chapter 4, was that having access to GP records had given them more information than in the past about the claimant's health condition. For long-term claimants the outcome had sometimes been a call for medical examination, whereas in the past, they might have been passed at the scrutiny stage.

For other claims, re-referral dates were set for longer periods than might have been the case under the usual arrangements. Typically, in the past, long-term claims would have been assessed on somewhat out-of-date information in the claimant's case file, perhaps supported by an IB1 13 that recorded only 'no change' in their condition.

The implication drawn from this experience was that there might be, in the wider incapacity benefit claiming population, claimants who, if assessed fully in a face-to-face medical examination, would no longer meet the Personal Capability Assessment thresholds. If the pilot arrangements were extended nationwide this might lead to an increase (though possibly temporary) in disallowances at the re-referral stage and a rise in appeal levels.

### 7.1.9 Appeals

One of the hoped for outcomes of the pilot arrangements was a decrease in the number of appeals lodged by unsuccessful claimants, and a reduction in the proportion of appeals that eventually succeed at a tribunal. The rationale for this was that the pilot arrangements would produce better, more accurate decisions because they would be based on information extracted directly from GP records. If this was understood by unsuccessful claimants then there would be greater confidence in, and acceptance of, disallowances. Furthermore, if appeals were still made then the decision was more likely to be upheld at a tribunal.

This research project was not designed to evaluate what impact the pilot was having on appeals. (Further work in this area will be carried out in 2003 and reported separately.) However, approved doctors and Jobcentre Plus staff were asked about their views about the impact on appeals. From those who felt able to offer a perspective there was an emerging view that the pilot arrangements are unlikely to have much of an effect at the appeal level. There were two main reasons for this.

First, the motivation for claimants to appeal, particularly in the view of Jobcentre Plus decision makers and processing staff who may have contact with them, has little connection with the soundness of the original decision. From their experience, claimants are rarely interested in understanding decisions but in getting them changed. Furthermore, decision makers said that if the occasion arose under the pilot arrangements they would almost certainly not mention to a claimant that they had seen an extract from their GP records. This echoes the comments of EMOs, who were clear that they did not, and would not, tell claimants the exact nature of the medical information before them (in order not to risk GP-patient relations). Hence if claimants are not told (or reminded if they knew at some stage) about how GP records have fed into the decision, then such knowledge cannot persuade them that the decision was correct.

Secondly, there was a degree of concern expressed about the decision-making processes of tribunals. In the perception of some research participants, tribunals are sometimes unduly influenced by what appellants tell them or new information provided by third parties and pay less attention to the information used in making the original decision. There was little confidence, therefore, that clinical information contained in the SB2 extracts from GP records would change this.

## 7.2 Lessons for running pilots

As mentioned earlier in the report, some of the research participants commented positively on being invited to participate in a pilot exercise and saw this as a sensible and appropriate way of informing and developing public policy. Some also made specific comments about how the pilot was being run that could be useful in thinking about the use of pilots in the future.

Robust projections about numbers and types of likely pilot participants are important to avoid major changes to design and timetable. Staff need to be kept fully informed about the pilot not only in advance of its commencement but also when changes are made to the pilot design later. In this pilot, not all staff were aware of the extended timetable or the inclusion of re-referral claimants (these changes are described fully in Appendix A). Staff who are involved in putting the pilot arrangements into practice said they would have welcomed more support and guidance. Smooth running of pilots depends partly on the commitment and effort of a range of staff and can be jeopardised by drops in morale or feelings of isolation. Staff working in Jobcentre Plus offices need to be informed about pilot arrangements also. It is likely that they will have to deal with some enquiries during the period of a pilot from participants. Many research participants were interested to hear about the progress of the pilot. Early thought needs to be given as to how feedback to all the participant groups will be handled. Telling people what and when they will receive this could contribute to level of participation and help to maintain commitment during the pilot.

### 7.3 Views on improving the collection of medical information

All the research respondents were invited to reflect on the best way of collecting medical information and whether they could think of improvements for the future. Respondents naturally gave their views from a number of different perspectives (for example, as pilot participants or non-participants) and from different knowledge and experience bases. The ideas and suggestions generated are summarised below and are intended as a stimulus to policy thinking. It was beyond the remit of the respondents and beyond the scope of the research project to evaluate or cost them.

The suggestions made fell into three broad groups:

- Ideas based on continuing with the current arrangements based on IB1 13 forms.
- Ideas based on the pilot arrangements.
- Other ideas, not specifically related to the usual or pilot arrangements.

These are discussed below.

#### 7.3.1 Ideas based on continuing with the current arrangements based on IB1 13s

Some people taking part in the pilot preferred the current arrangements of collecting medical information to the pilot arrangements. For some there were fundamental objections of principle to the pilot. For others their view was based more on the utility of the information contained in IB1 13 forms compared with SB2 extracts. There were problems with the number of IB1 13s returned by GPs and with the quality of many that were returned. Suggestions were made for tackling both these deficiencies in the current arrangements. In addition there were suggestions about revising the IB1 13 to increase its utility further.

Four ideas emerged for increasing the flow and quality of IB1 13s from GPs:

- Introduce payments for completion.
- Invoke management action for non-compliance.
- Introduce better quality control procedures.
- Introduce better training for GPs.

GPs are required to complete IB113 forms as part of their NHS terms of service and payment for this work is included as part of their overall NHS remuneration. This method of payment, through the GP's general salary, contrasts with the method of payment for some other medical reports, including other reports requested by the DWP. Requests for reports originating from the private sector, for example, from solicitors or insurance companies, usually generate a separate fee which is paid directly by the party requesting the report. One suggestion was to rationalise payment for all state social security benefit related reports and to pay an item of service fee for IB113 forms. It was suggested that such a direct fee could act as an incentive to some GPs. An alternative, but not mutually exclusive, view was to reaffirm that GPs have a contractual duty to complete IB113s and to invoke management procedures against GPs who consistently fail in that contractual duty.

In itself, it was recognised that increasing the number of IB113s returned was not sufficient. Quality also needed to be improved. This could be attempted by the introduction of quality control procedures that might, but need not, be linked either to a system of fees or management responses.

A different approach suggested was to introduce a better programme of training for GPs. This could include informing GPs of the importance to their patients of their contribution to the evidence gathering process for state benefits and educating them about the type and depth of information that is required from them. Factual evidence from the GP can make an important contribution to accurate decision making and the financial wellbeing of people can be a legitimate clinical concern. The aim of such a programme would be to encourage GP compliance and commitment, and to improve the quality of the information on IB113 forms. We have shown that some GPs take very seriously the task of completing IB113 forms for their patients. There may be lessons to be learned from such GPs about why and how they have this level of commitment which could be used in publicity or training to increase the commitment of other GPs.

There were several respondents who suggested that a review of the IB113 form itself was needed. We have shown above that many GPs find some sections or questions difficult to respond to. There were few specific suggestions for change but rather a more general feeling that if the form irritated or alienated some GPs then some reform was certainly appropriate. Two suggestions were that the IB113 should have more direct questions about functionality, and that there should be space for benefit or medical staff to add questions specifically relating to the individual claimant's circumstances. Suggestions such as these however would not in themselves address the criticism of some GPs that, in the course of treating patients, they do not necessarily accumulate knowledge about functionality.

### 7.3.2 Ideas based on the pilot arrangements

It was recognised that in the design of the pilot arrangements the problem of non-compliance (i.e. in relation to the completion of IB113 reports) among the GP participants, which undermines the current arrangements, is effectively eliminated. Suggestions for building on the pilot arrangements were therefore aimed more at increasing their operational effectiveness and efficiency. It will be apparent from the section on policy issues above that these suggestions would not command unanimous support from the research respondents in this study.

The range of ideas, which are largely self explanatory, included:

- handwritten extracts from GP records should be transcribed to overcome legibility problems faced by EMOs and decision makers;
- extracts in SB2 forms should be sorted chronologically according to condition, to assist and speed understanding by EMOs and decision makers;

- extracts should be annotated with explanations of difficult, obscure or unusual medical terms;
- the period for which information should be extracted, at least for new claims, could be restricted to one or two years;
- information should be sought where appropriate from other health, support and care professionals involved with the claimant.

It was recognised that the success of using GP records in incapacity benefit decision making depended largely on the quality of the raw material, but as we have mentioned earlier, GP records are very variable in quality. A suggestion for responding to this was that staff in Medical Services or Jobcentre Plus should be authorised to ask (or require) GPs to complete an IB113 in cases where the GP record was insufficient for benefit purposes.

### 7.3.3 Other ideas

One idea for improving clearance times of incapacity benefit was to combine the two stages that occur in the Medical Services Centre into one. At present, approved doctors handle some cases twice, first to provide advice about exemption, and for non-exempt cases, to provide advice a second time when the claim is scrutinised. In this process IB113s and Med 4 statements from GPs, or the GP records under the pilot arrangements, and IB50s from claimants, are requested at separate times.

A combined process would require GPs and claimants to supply information concurrently and thus save possibly several weeks in dealing with the claim. It was acknowledged that this would result in all claimants being asked to complete a Personal Capability Assessment, including people with severe physical and mental conditions who are currently not required to do so.

A different idea emerged from a reflection of developments in other areas of the welfare to work policy area. Current benefit and employment policy is aimed at helping as many people as possible into or back into work after a period of absence from the labour market because of sickness or disability. It is possible that services aimed towards the rehabilitation of claimants will increase as a result of the current policy direction. The records kept by rehabilitation services on individual clients, which can be expected to contain information about functionality, might therefore become an important additional source of information for benefit purposes.

## 7.4 Conclusions on research aims

The medical evidence gathering pilot was set up as a response to the known shortcomings in the existing arrangements for collecting and using medical information in making decisions on claims for incapacity benefit. In this section we return to the research aims that formed the starting point for this study and summarise the findings from the study, and offer some final reflections on developments in the future.

### 7.4.1 Impact on GPs

Few GPs said they had noticed any effect on their own work. Those who did notice a reduction in their workload included GPs in smaller practices, those whose practice received above average numbers of IB113 forms, and those who chose to spend time completing them fully. Generally these GPs welcomed the pilot for reducing the burden of paperwork.

The work of administering the pilot in the practice premises fell to practice managers and other administrative staff. The experience was variable, but for most it was unproblematic and manageable.



Practices adopting the photocopying option had experienced the greatest impact in terms of increased work, disruption of normal working schedules and financial impact.

Participating GPs were still generally in favour of the pilot arrangements when interviewed, and some non-participants were more favourably inclined towards the pilot after learning more about it from researchers and hearing about its impact in other practices. Some non-participating GPs still had serious concerns about confidentiality and informed consent. Other GPs maintained the view that they were the most appropriate people to provide medical information about their patients.

### **7.4.2 Quality of medical advice given to decision makers**

In general, decision makers reported little impact on the quality of medical advice from approved doctors in Leeds or the EMOs in Medical Examination Centres. The nature of the information from approved doctors had changed and was generally more difficult to understand and not so useful as information contained in IB113 forms. Little change had been noticed in the quality of the IB85 medical reports from EMOs.

### **7.4.3 Impact on decision making**

At each stage of the decision-making process the impact on decisions was felt to be small. There was a general view that benefit decisions on pilot cases would have been the same if made under the usual arrangements. Approved doctors perceived that at the scrutiny stage they had advised examination in a higher proportion of pilot cases compared with non-pilot cases. However, there was no evidence from this research to suggest that final benefit outcome decisions differed between the two groups.

There were, however, reports from some approved doctors, including EMOs, and decision makers that they had more confidence in some of the advice offered or decisions made on pilot cases because of the medical information available from SB2 extract of the GP records. Some EMOs also reported that they had been able to provide better informed advice about re-referral dates on some pilot cases.

### **7.4.4 Overall effectiveness of the new procedures**

The procedures put in place for the operation of the pilot generally worked well in GP practices and the Leeds Medical Services Centre and the Medical Examination Centres. None of the GPs or practice staff reported problems with the procedures or had experienced difficulties when GP records were away from the practice premises. Sometimes this was due to the back-up procedures that the practices had introduced themselves. The courier firm used in the pilot was commended by some GP practice staff for its efficiency and professionalism. No problems with the collection or return of GP records were reported. In contrast, some staff in the Jobcentre Plus offices taking part in the pilot experienced difficulties, frustration and delays in implementing the mainly manual procedures used in the pilot.

## **7.5 Final comments**

The pilot was set up with two main objectives: to reduce GP workloads, and to improve the quality of incapacity benefit decision making. It was designed also to be acceptable to GPs and to incapacity benefit claimants.

From the evidence presented here the pilot appears to have had mixed results. Most of the GPs and claimants interviewed found the pilot arrangements acceptable in principle and workable in practice. Some holding this view still had some concerns but did not report any adverse experiences. In contrast, there were GPs and claimants who held strong and serious objections to the principle of the pilots. The



pilot, by its design, reduced the number of IB1 13 forms sent to GPs participating in the pilot. The effect at the level of the individual GP was only noticed in particular practices, some of which may be atypical in terms of their size and their internal working practices.

Among the users of medical information, approved doctors who prepared the SB2 extract were closest to the raw material of the GP records and found the information the most useful. At other stages of the process the impact of the pilot lessened. EMOs generally found the information interesting but it did not contribute greatly to their examination of claimants or their choice of descriptors. There was no consensus among the EMOs interviewed about which set of arrangements was preferable. For decision makers, the SB2 information was generally of less use than information on IB1 13s. This group of staff was the least in favour of the pilot arrangements, but some had difficulty expressing a preference between a system that generated useful information on only a minority of cases and a system that promised less useful information but on all cases.

This study has produced a range of findings, some of which were unexpected, and raised a number of important issues that must be taken into consideration in the development of incapacity benefit procedures in the future. Those issues have been mainly raised by GPs, claimants, and staff of Medical Services and Jobcentre Plus demonstrating the considerable interest in the pilot from all these groups. Other issues have arisen in the course of analysis. At the time of writing a consultation period on the reform of incapacity benefit has just ended. We can therefore expect that further policy ideas and changes about the administration of the benefit will be likely to attract a high level of attention and debate.

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# Appendix A

## Research methods

### A.1 The pilot location

The pilot was conducted in the Sheffield and Rotherham area. This includes urban and rural settings with a range of socio-economic characteristics. Inner city and urban locations include areas with relatively high levels of benefit receipt; areas with high proportions of residents of minority ethnic background; and ex-industrial areas with relatively high levels of morbidity. Rural locations include ex-mining villages, and some higher income 'commuter' villages.

In the pilot area, most initial and ongoing claims for incapacity benefit are dealt with in the Sheffield and Rotherham Jobcentre Plus offices. Approved doctors who scrutinise the medical evidence supporting claims are based in Leeds; medical examinations are conducted in the Medical Examination Centres in Sheffield, Rotherham and Doncaster.

### A.2 Preparatory visits

Two preparatory site visits were undertaken, one to the Sheffield Jobcentre Plus office and one to Leeds Medical Services Centre. The purpose of these visits was to allow the research team to understand better the practice and procedures of the decision-making process under usual and pilot arrangements. The visits informed the design of the topic guide for all the groups interviewed. The visit to Sheffield Jobcentre Plus involved a meeting with the benefit manager for the medical referral team, two benefit processing staff and one decision maker. At the Leeds Medical Services Centre the research team met three members of the Schlumberger Sema project team; the operational manager; and two doctors engaged respectively in scrutiny, and medical examinations and training.

## A.3 Interviews with GPs and practice staff

### A.3.1 Building a study group

The aim was to conduct interviews with the senior or sole GP in 18 practices which had taken part in the pilot, and 12 practices which had chosen not to participate. The intention was to include men and women; a spread of ages among GPs; and a range of practice size (number of patients) and location, all of which might have some bearing on decisions to participate in the pilot, and experience of implementation.

An additional aim was to conduct interviews with key administrative staff in ten practices which had taken part in the pilot and whose GP was also interviewed.

Data supplied to SPRU for selection of a study group came in the form of one list of practices taking part in the pilot, and another list of those who were not. The lists included names and addresses of practices, and the names of the senior partner and other GPs in the practice. Also included for each practice was a name and telephone number for contact purposes, in most cases that of the practice manager or secretary. It thus proved not possible to determine a GP's age or number of patients in advance of selection, although the number of GPs attached to a practice gave some indication of relative size.

Initial study of the lists of GPs suggested that there were more large multi-practitioner practices among participants than non-participants, and conversely, that there were more single GP practices among the non-participants. It was eventually decided, therefore, to sample participant and non-participant GPs so that each sub-group included:

- men and women;
- practices in a range of locations, including urban areas known to have minority ethnic populations;
- some single practitioners;
- some senior partners in multi-practitioner practices.

The actual location of each practice listed was marked on a large scale map of the area. Using the above criteria, 30 practices were selected from 67 documented as taking part in the pilot; and 24 practices from 77 recorded as non-participants. SPRU sent letters to the senior or sole GP in each practice, inviting them to take part in a research interview. Included with this letter was a summary of the overall research design, and a further explanatory letter from the Department for Work and Pensions (in Appendix C). Letters were mailed in the first week of October 2002, and quickly followed up by telephone calls to arrange appointments. Permission to interview key administrative staff in participating practices was also sought during this telephone call, and arrangements made in advance or on arrival in the practice.

Achieving these interviews required some persistence. Some GPs were hard to reach and one or two had retired or died. A slightly higher proportion of GPs who did not take part in the pilot than those who did declined a research interview. Those GPs who preferred not to be interviewed generally said there were other priorities on their time. Two GPs who did not have time for an interview gave their views by telephone, and these discussions are included in the analysis. In four practices, the researcher was directed to the practice manager, as the person with the main responsibility for, and knowledge of, the pilot, who would represent the general views within the practice. Included here were some participating practices in which the GP had no initial recollection themselves of any pilot arrangements.

Altogether, interviews were achieved in GP practices as shown in Table A.1

**Table A.1 Recruitment of GPs and practice staff**

	Practices participating in pilot	Practices not participating in pilot
Practices notified to SPRU	67	77
Invitation letters sent	30 (31)*	24 (23)*
No contact made with named senior partner	11	8
Declined to take part	3	3
Interviews achieved:		
personal interview with GP	14	9
personal interview with practice manager, instead of GP	3	1
telephone interview with GP	-	2
personal interviews with additional practice staff	10	-

\* One GP from the non-participant list was discovered to be taking part in the pilot

The researchers used topic guides (copy in Appendix B) to steer discussions across the main areas of interest:

- characteristics of practice, and respondent;
- knowledge of the pilot, and views;
- reasons for taking part in the pilot, or not;
- effects of the pilot arrangements;
- experience of 'non-pilot arrangements' for supplying medical evidence;
- views on improving collection and use of medical evidence.

Personal interviews with GPs and practice managers on behalf of GPs generally took 30-45 minutes. Interviews with additional practice staff generally took slightly less time. An honorarium of £75 was paid to the senior partner in practices in which personal interviews were conducted. Personal interviews were tape-recorded, with permission, and transcribed for analysis.

The telephone interviews were fairly short, to suit the GPs, and the researchers made notes during the conversation.

### A.3.2 The study group: characteristics of GPs and practice staff

GPs in the study group included men and women, with different lengths of time in their current practice, and varying lengths of experience as a GP. Some were from minority ethnic backgrounds. The study group included four single practitioners, four GPs in two-partner practices, and several GPs in large practices with five or more partners, salaried GPs and a range of nursing/medical staff. All practices had at least two administrative/reception staff, and some large practices had more than 20 administrative/clerical and reception staff, often working part-time. One practice taking part in the pilot was operating from two sites.

The practices covered urban and rural areas in and around Sheffield and Rotherham, with a range of socio-economic characteristics. Some GPs reported relatively high levels of unemployment, social deprivation and morbidity among their patients; others said that their practice contained only small pockets of social deprivation, and employment was generally high. The study group included GPs practising in areas where many patients came from minority ethnic backgrounds.

Additional practice staff interviewed included practice managers, administrative staff and clerical/reception staff. This group included men and women.

## A.4 Interviews with Incapacity Benefit claimants

The aim was to talk to people who had agreed that their claim for incapacity benefit should be dealt with under the pilot arrangements **and** whose GP was participating in the pilot, and people claiming incapacity benefit who had declined to take part in the pilot. The decision was taken not to seek interviews with any incapacity benefit claimants whose GP had agreed to be interviewed for this qualitative research, for reasons of confidentiality and to encourage participation on both sides. This meant that sampling for recipients took place after deciding which GPs would be invited to take part in this research although the interviews with claimants actually took place before interviews with GPs and practice staff.

Developments in the implementation of the pilot affected the sampling strategy. Initially only claimants undergoing the PCA for the first time were included under the pilot arrangements, which began in January 2002. From April 2002 benefit recipients who were facing a second or subsequent PCA were recruited to the pilot, in order to boost the participant sample size. For purposes of description, we use DWP terminology and call the latter group (PCA) 're-referrals'.

The eventual aim was to achieve interviews with:

- 12 people making a 'new claim' who had agreed to take part in the pilot;
- 12 people facing a second or subsequent Personal Capability Assessment (re-referred) who had agreed to take part in the pilot;
- 12 people who had declined to take part in the pilot, of whom:
  - 6 were making a new claim; and
  - 6 were making 're-referred' claims.

It was known from previous research that has investigated claimants' views about how their claims are processed that people's assessments are often influenced by the outcome of their claim. The aim was thus to interview the incapacity benefits claimants before they received a decision. This required inviting recipients to take part in the research as soon as possible after the start of their claim. A flexible approach was required which enabled the research team to respond immediately to notifications by DWP of appropriate claimants, within an initially unspecified 'trawl' period, long enough for numbers to build of claimants going through the pilot.

The approach adopted was as follows. From May 2002 the DWP research management team sent to SPRU fortnightly lists of people claiming incapacity benefits in the Sheffield and Rotherham area. Claimants were distinguished according to whether they had agreed to take part in the pilot or not. Immediately on receipt of each list, letters of invitation from the DWP were sent from SPRU. The letters (Appendix C) reminded people about the trial to test new ways of getting medical information from their GP. It went on to invite them to take part in some research, to find out why they had decided to be in the trial, or not, and what they thought about medical records being used in this way. The opportunity was offered to opt out of the research, either to research managers in DWP or the SPRU research team secretary.

After two weeks, those people who had not opted out of the research were considered for inclusion in the study group. The researchers attempted to contact people quickly, mainly by telephone or

direct calls at their address. Some letters were also sent, inviting people to get in touch with the researcher to make an appointment. The latter approach was used when telephone contact was not possible.

The fieldwork continued in this way until the end of September, sending fortnightly waves of invitation letters followed up immediately after a two week opt-out period. A purposive study group was built as described in the following section.

#### **A.4.1 Building the study group**

As described above, the aim was to recruit people who had and had not agreed to take part in the pilot; and people making new claims and those who had been re-referred, who had not yet received a decision about their claim. The researchers explained to those people contacted who had already received a decision that they were not among the group of people whom the researchers hoped to talk to. It was decided in advance that if any such people strongly wished to take part, interviews would be arranged for them. In the event, this was not necessary, although one or two people said they were disappointed not to be included.

Selection of people with home addresses across the Sheffield and Rotherham area led to the inclusion of patients from different practices. The researchers aimed to include similar numbers of men and women, with a spread of ages; to include people with a range of impairments and health conditions, and at least some people who had been assessed for Income Support or National Insurance credits (characteristics reported in the lists of names supplied to the research team). The aim was to include some claimants from minority ethnic backgrounds. People's names sometimes provided an indication here. An additional aim was to include people facing a Personal Capability Assessment for the first time and people who had had a previous experience, but it was not possible to select on this basis. Some of those making a 'new claim' (i.e. from a period of non-claiming) had claimed incapacity benefits in separate claiming spells, sometimes several years previously, which was not known to the researchers in advance of the interview.

#### **A.4.2 Response**

It is not possible to report a 'response rate' in the way that is traditional in this kind of recruitment to research, for a number of reasons. Most important is that we do not know whether those who initially opted out or those who declined an interview when contacted by the researchers were actually in scope. Such people often explained quickly that they were too busy to take part or not interested in the research, and it was often then inappropriate to go on to ask them if they had received a decision about their claim. Thus, those declining an interview probably included a number of people whom the researchers would not have sought to include anyway. Indeed, people dissatisfied with the outcome of their assessment may have been less inclined to take part in the research, and those already in work may have had more constraints on their time.

An additional factor is that we do not know whether those people who had answerphones running when the researchers telephoned actually received messages left for them, inviting them to get in touch to arrange an appointment. Many people on the lists supplied had answerphones set up. Not replying to the researcher's message might have been a way of declining to take part in the research, so the researchers did not try again if two or three messages elicited no reply. It is also possible, however, that such messages just never reached the people for whom they were intended, for example, if a person had moved home, was in hospital or on holiday, or if somebody else in the household decided not to pass on the message. This also applies to recruitment attempted by letter.



We can make the following observations about the recruitment of incapacity benefit claimants for this study. A high proportion of the people listed were not accessible by SPRU by telephone. It was common for people to be ex-directory, probably related to increasing ownership of mobile telephones as well as preference for privacy. It was not unusual for telephone numbers listed by DWP to be out of use. It was not unusual for telephone numbers which were reached to have answerphones running, for what appeared to be large parts of the day and early evening. The researchers felt that this may be an indication that increasing numbers of people now choose not to answer their telephone immediately, even when at home, but to scan incoming calls and decide whether to respond.

Those people who did decline personally did not always give a reason. Some said they did not have time, as a result of work commitments or caring responsibilities; did not feel well enough; or preferred not to take part because they did not like meeting new people or answering questions. Some simply said they were not interested. Sending letters inviting people to get in touch with the researchers rarely resulted in an interview. Making a first contact by calling at a person's home was usually successful in terms of recruitment for an interview, but was resource intensive.

### A.4.3 Conducting the interviews

The researchers asked all those invited to take part where they would like to meet, and whether any special arrangements would make it easier for them to take part in the research. All preferred to be interviewed at home; some preferred to take part with their domestic partner. Nobody took part with an interpreter or signer. One interview was conducted by telephone because the person concerned preferred the researcher not to visit.

Topic guides (Appendix B) were used to steer discussion across the main topics of interest:

- Personal circumstances; employment and claiming histories.
- Awareness and understanding of pilot arrangements; reasons for taking part or not.
- Understanding of decision making processes in medical assessments.
- Previous (non-pilot) experience of medical assessments.
- Views on pilot arrangements.
- Views on medical examinations.
- Improving collection and use of medical information.

Interviews varied in length. Discussions were shorter when people had little awareness of, or interest in, the pilot arrangements or the general process of medical assessment for benefits purposes. If people were interested in the issues and had experiences they wanted to tell the researchers, interviews could take up to one hour and a half.

The discussions (including the telephone interview) were tape-recorded, with permission of respondents, and transcribed for analysis. Those who took part in the research received a gift of £20 to acknowledge their help.

#### A.4.4 Characteristics of the claimant study group

The study group of 32 people included 22 people recorded by DWP as taking part in the pilot arrangements, and ten people recorded as non-participants. According to DWP records, representation of people making 'new claims' and those who had undergone a previous medical assessment in their current claim, or been 're-referred', was as follows:

**Table A.2 Membership of the study group**

Pilot participants		Pilot non-participants	
New claims	Re-referred	New claims	Re-referred
12	10	7	3

The group included 21 men and 11 women, as shown in Table A.3. This largely reflected the composition of the sample supplied to SPRU. According to general administrative statistics supplied by DWP, 62 per cent of the incapacity benefit population in October 2002 were men.

The researchers initially aimed at a more equal balance between men and women in the study group, but there were fewer women who might be approached for interview, especially among people who had been re-referred.

**Table A.3 Men and women in the study group**

Pilot participants		Pilot non-participants	
Men	Women	Men	Women
14	8	7	3

The study group included people from all age ranges, as shown in Table A.4. In terms of comparison with the general incapacity benefit population, our study group had fewer people in the age range 50-59 years, and slightly fewer aged under 30 years.

**Table A.4 Ages of people in the study group**

	Pilot participants	Pilot non-participants
Under 30 years	1	-
30-39 years	7	3
40-49 years	6	3
50-59 years	4	2
60 years and over	4	2

People's family and household circumstances may influence their views about medical evidence and incapacity benefits. For example, claimants may have discussed with a partner whether to take part in the pilot; or responsibility for dependent children may influence people's views on the outcome of a Personal Capability Assessment. Table A.5 shows the family and household circumstances of claimants in the study group. Fifteen of the claimants were owner-occupiers; 12 local authority tenants; four had private landlords and one was a housing association tenant. One person had a minority ethnic background.

**Table A.5     Family and household circumstances**

Lives with partner	11
Lives with partner and dependent children	7
Lone parent	2
Lives with partner and adult relatives	4
Lives with adult relatives	1
Lives alone	6
Lives with person as their carer	1

**A.4.5     Health and impairment**

The aim was to achieve a study group which included people from a number of broad categories of health conditions and impairments. Most people interviewed talked about current health circumstances or impairments which affected their capacity to work. People often spoke of a number of different aspects of current ill-health which affected daily living in a number of different ways. One example was managing limited mobility due to severe arthritis at the same time as dealing with clinical depression. We made no attempt to categorise people in the study group in terms of diagnoses of illness, or type of condition. As a result of what people told us, however, we know that the study group included people with musculo-skeletal conditions; respiratory and circulation problems; multiple injury; epilepsy; diabetes; sensory impairment; different kinds of mental illness (depression, anxiety, phobias, psychosis); cancer and other progressive illnesses; and drugs or alcohol dependence.

The Sheffield/Rotherham area has a history of industrial and mining employment, and there are still some areas of concentration of heavy industry and manufacturing. As we might expect, some of the men in the study group had experienced serious industrial accidents and injury.

In some cases, symptoms of current illness affected the conduct of the interviews. For example, some people were distracted by pain or fatigue. Some found it hard to maintain discussion, due to severe depression, and some became tearful and needed time to re-engage with the interviewer. One person's views were possibly affected by paranoia. Some people explained poor recall of events and lack of concentration in the interview as due to effects of powerful medication, brain injury or stroke. In all such cases, the interviewers did as much as possible to prevent the interview being a negative experience, and this sometimes meant not pursuing issues which were sensitive, or conducting a shortened interview. We have taken account of the above factors in the analysis. Material from all the interviews was valuable.

**A.4.6     Employment and benefits**

In terms of benefit receipt and entitlement, most people were being assessed for incapacity benefit when selected for the study group. The group also included some people who had been claiming Income Support with a disability premium because they had insufficient contributions for eligibility for Incapacity Benefit. A number of people were also receiving industrial injuries allowances, and the study group included recipients of Disability Living Allowance. Not everybody was certain which benefit they were claiming, however, and it is not possible to present a systematic analysis of benefit receipt. Although the aim had been to interview only people who had not yet received a decision in their current claim for incapacity benefits, it appeared that a few respondents had actually been told the decision by the time they met the researcher.

There was a wide range of views about the possibility of returning to paid employment. Those who thought returning to work was unlikely included:

- people who said that their hospital consultant had advised not to go back to work;
- people facing a progressive illness or deteriorating condition;
- people very close to retirement age.

Those most keen to return to work included people responsible for children and people who had a long employment history and disliked the inactivity and boredom involved in being away from a workplace. Included in the latter group were some of the oldest men interviewed. By the time of the interview, one man was about to start work using permitted work rules; another was considering a job offer, and another had started applying for jobs. A person who had just been told that his incapacity benefit was going to be withdrawn, after a Personal Capability Assessment, said he was resigned to having to look for a part-time job.

Two women still had contracts of employment and hoped eventually to return to their employer, perhaps with an adjustment of activities at work. Two of the younger members of the group were aiming towards higher education rather than paid work, when their condition improved.

## A.5 Group discussions with incapacity benefits processing staff

In discussions with the appropriate line managers in the Sheffield and Rotherham Jobcentre Plus offices it was possible to identify all staff involved in some way in the processing of incapacity benefit claims. Managers were asked to nominate staff who could attend and contribute to a group discussion on the basis of having a reasonable amount of experience of the pilot arrangements. It was recognised that organising the release of staff from busy sections might cause some disruption so no other selection criteria were imposed.

The discussions with processing staff took place in mid-November 2002, when the pilot had been running for nearly one year. There were three discussions, in different Jobcentre Plus offices in Sheffield and Rotherham. Altogether, ten members of staff took part, all but one of whom were women. All were administrative officers, engaged solely or partly with medical administrative work, and most had been in post throughout the lifetime of the pilot.

One researcher moderated each discussion, using a guide (Appendix B) to steer discussion across the topics of interest:

- Practice in processing claims: pilot and non-pilot arrangements.
- Impact of pilot arrangements.
- Strengths and weaknesses of pilot arrangements.
- Suggestions for improvement.

The group discussions worked well. Respondents from each different office generally worked together as a team, and were used to sharing their views in a group setting. The discussions were tape-recorded, with permission, and transcribed for analysis.

## A.6 Discussions with decision makers

All decision makers working on incapacity benefit claims were identified in discussions with the appropriate managers in the Sheffield and Rotherham Jobcentre Plus offices. The intention was to include, in this phase of the research, all decision makers apart from the person who had already participated in the research in site visit discussion earlier in 2002. Managers were asked to nominate two officers from their respective offices to take part in a group discussion. Other decision makers would be asked to participate in a one-to-one interview.

Six decision makers were thus interviewed individually and four took part in the group discussion. Over the course of the research, therefore, all decision makers working on pilot cases took part in the research. Fieldwork was carried out in November 2002. One member of the research team moderated the group discussion.

The aim of the one-to-one interviews was to explore individual practices and experiences of making incapacity benefit decisions under both the pilot and the usual arrangements. In contrast, the group discussion was used to explore what medical information decision makers need to do their job and to think about how this might be organised in the future. Topic guides are included in Appendix B.

Topics covered in the individual interviews included:

- The role of the decision maker.
- The impact of the pilot arrangements.
- Strengths and weaknesses of the pilot arrangements.

Topics covered in the group discussion included:

- Information needs of decision makers.
- Views about collecting medical information in the future.
- Preferences for working with usual arrangements or pilot arrangements.

Both the individual interviews and the group discussion worked well. All discussions were tape-recorded, with permission, and transcribed for analysis.

## A.7 Interviews with Medical Services staff

Interviews with approved doctors in the Leeds Medical Services Centre were organised through the operational leader with responsibility for administering the pilot. All four doctors who were in post and carrying out work connected with the pilot in November 2002 were interviewed. Interviews with Examining Medical Officers (EMOs) were arranged through the manager of the Sheffield Medical Examination Centre. All six of the EMOs who were seeing pilot cases regularly were interviewed. In agreement with DWP, one EMO, who had seen only two claimants under the pilot arrangements, was not interviewed. An interview with the operational manager for the pilot was arranged directly with her.

A single topic guide (see Appendix B) was used in the interviews with approved doctors in Leeds and with EMOs. The researcher used appropriate sections according to the role of the individual being interviewed. Topics covered included the following:

- Background and experience.
- Extracting information from GP records.
- Experience of making decisions about exemption.
- Experience of carrying out the scrutiny stage in the decision making process.
- Experience of carrying out medical examinations.
- Views about how medical information could be collected in the future.

Topics covered in the interview with the Medical Services Centre operational manager included:

- Impact of the pilot arrangements.
- Strengths and weaknesses of the usual and pilot arrangements.
- Lessons learned from the pilot for the future administration of incapacity benefit claims.

All interviews with Medical Services staff worked well. Discussions were tape-recorded, with permission, and transcribed for analysis.

## A.8 Analysis

Analysis of material from each part of the research was handled separately, but the approach was similar in each case. Analysis began with reading the transcripts or tape-recordings and additional fieldnotes, and arrangement of material under key headings, reflecting the main topics for enquiry and additional themes emerging from the data. A series of thematic charts was drawn up, for each set of transcripts, and data from each transcript summarised under the appropriate heading.

The method has been developed and refined within SPRU over many years, alongside the 'Framework' approach (Ritchie and Spencer, 1994) initiated by Social and Community Planning Research, now the National Centre for Social Research, which takes a similar analytic approach in the context of conducting applied qualitative research.

Ordering data in this way means that, in the case of interviews with individuals, the accounts of all respondents can be explored within a common thematic framework, grounded in the data collected. It helps to highlight the full range of perceptions, beliefs, experiences and behaviours described by the respondents, and enables exploration of the factors which underpin them. The method enables within-case and between-case analysis, essential for drawing out a full interpretation of the data. The final stage of the analysis involves reviewing the data mapped in the thematic matrix; comparing accounts from individuals, and identifying patterns and explanations within the data. A similar approach was taken with analysis of transcripts from group discussions, which identified contributions from individual members of the groups.



# Appendix B

## Topic guides

### TOPIC GUIDE

#### Interviews with participating GPs

##### Interviewer's introduction

*You were invited to take part in this research because you/your practice are participating in the Department for Work and Pensions trial to test a new way of collecting information for deciding whether people are eligible for incapacity benefits. We would like to hear about your views and experience of the trial.*

- Remind about SPRIU
- Explain the issues to be covered
- Discussion will last around one hour
- Explain confidentiality, and how the material will be used
- Ask for permission to use tape-recorder
- Any questions or concerns?
- Give money gift.

##### 1. Employment history, information about practice

- Time as GP
- Time in this practice
- Number of GP sessions/week

*(Ask multi GP practices only)*

- 'Personal list' of patients or 'shared practice list'
- Number of patients (practice, self)

##### 2. Knowledge of trial

- How did you learn about the trial?
- How was rationale for trial explained?
- How is the trial being conducted?
  - what gets sent, to whom
  - what happens to information
  - how quickly are notes returned
- Views about patients' notes being used in this way

##### 3. Reasons for taking part in the trial

- Initial view
- How was it decided?
  - involvement of colleagues, practice staff
- Decision to send case files or photocopies
  - Explore

##### 4. Effects of trial

- On workload
- On administration of the practice
  - extra work? for whom?
  - costs?
- Any impact on patient care and on ability to do own job
- On relations with patients who are claiming a state benefit
- Have they been contacted by Medical Services doctors in Leeds/Sheffield to discuss administrative aspects of the trial, or individual patients in the trial?
  - reason? views.
- Are arrangements for transporting notes and returning them working smoothly?
  - how could difficulties be overcome?
- Any feedback from individual patients?

##### 5. Experience of usual arrangements

[NB GPs will still be filling in some IB 113s for claimants who opted out of the trial]

- How many medical statements (e.g. Med 3) do you usually issue each week? How many of these are for people with ongoing disabling conditions?
- How many (or what proportion) of your patients do you think are currently in receipt of a state incapacity benefit?
- Overall how much work does benefit related work usually amount to for you each week (on medical statements, medical reports and related appointments with patients)?
- What is the process of completing IB113?
  - dealing with IB113 in practice
  - any guidance available/used
- Views about filling in form IB113
  - time taken per week
  - any questions that GPs find particularly difficult to answer
    - Probe: what is difficult



- Does more information go into the IB113 than is accessible in the patient's notes? *Probe*
- How far do you think the information you provide on the IB113 can influence the outcomes of claims?
- Do you form a view about whether patients should receive IB?
- Are there any advantages or disadvantages in completing a statement that is handed to the patient, like a Med4, compared with an IB113 which the patient does not see?

#### 6. Comparison with similar arrangements

- Usually, in your practice, are patients' notes used by anyone else outside the practice?  
     who? for what purpose?  
     views about patient notes being used in this way

#### 7. Improving collection and use of medical information for deciding incapacity benefits

- Knowing what you know now, would you have participated in the trial?  
     *Probe for reasons*
- How would you feel about it being introduced across the country as the new way of collecting clinical information on all patients who are on a state incapacity benefit?  
     *Probe*
- Are new arrangements appropriate for all incapacity benefit claimants or some only?  
     *Probe*
- How best do you think factual information about your patient's condition could be obtained to inform benefit assessments?

#### TOPIC GUIDE

##### Interviews with office staff of participating GPs

#### Interviewer's introduction

*You were invited to take part in this research because you/your practice are participating in the Department for Work and Pensions trial to test a new way of collecting information for deciding whether people are eligible for incapacity benefits. We would like to hear about your views and experience of the trial.*

- Remind about SPRIU
- Explain the issues to be covered
- Discussion will last 10-15 minutes
- Explain confidentiality, and how the material will be used.
- Ask for permission to use tape-recorder.
- Any questions or concerns?

#### 1. Background information

- Position/job title
- Other office staff
- Roughly, how many cases have been dealt with under trial arrangements?
- Is practice (a) sending case notes; (b) sending photocopies; (c) sending notes electronically?
- Were staff involved in the decision of the practice to take part in the pilot?

#### 2. Effects of trial

*Interview note: adapt questions accordingly for different means of supplying information.*

- What is the procedure for handling requests for notes?  
     how does request come to you?  
     who does what?  
     do you have to make any decisions/judgments about what to send?  
     *Probe*  
     how quickly can request be dealt with? Is it a priority task?  
     are GPs involved in any way?
- How do you keep track of notes?  
     explore manual/computer systems  
     how quickly are notes returned?  
     do you chase (late) returns?

- Are arrangements for transporting notes and returning them working smoothly?  
how could difficulties be overcome?
- Has trial had any effect on patients? *Probe*
- Has trial created any problems for you? *Probe*
- Overall, has the trial created much extra work? *Probe*
- Views about sending only a portion of the casenotes
- Any issues of confidentiality arising from pilot arrangements?
- Any suggestions for improving trial arrangements?

**TOPIC GUIDE**  
**Interviews with participating clients**

**Interviewer's introduction**

*You were invited to take part in this research because you have recently made a claim for incapacity benefits in the Sheffield/Rotherham area. In this area the Department for Work and Pensions is trying a new way of collecting information for deciding whether people are eligible for incapacity benefits. We would like to hear what you think about this.*

- Remind about SPRIU
- Explain the issues to be covered
  - about you and your household
  - about your recent (or continuing) claim for incapacity benefit (for which a decision is still awaited)
  - thoughts about the trial (whether you are taking part or not)
  - experiences of claiming incapacity benefit in the past
  - views about medical examinations (whether or not you have had one)
  - your ideas about how to improve how your claim is dealt with (might want to bear this in mind as we proceed)
- Discussion will last around one hour – check need for breaks
- Explain confidentiality, and how the material will be used
- Explain discussion will have no effect on current claim, on any other benefits, or dealings with DWP, Inland Revenue, Employment Service, Child Support Agency etc., or any dealings with your own GP
- Ask for permission to use tape-recorder
- Any questions or concerns?
- Give money gift.

**1. Personal circumstances, employment history, claims history**

**Details of household**

- household members; age
- responsibility for children
- tenure

### Employment/benefit history

(to explore experience of paid work and sickness/incapacity benefits, focusing on last two to three years)

- periods of employment; type of work
- claims for sickness/incapacity benefit
  - route onto IB (including type of illness/impairment)
- receipt of other benefits
- attempts to try/return to paid work
- current situation in respect of work and health

### 2. Awareness of taking part in the trial

[Interviewer note: Ask following question about awareness of being in the trial and route to appropriate set of questions. Refer to claim form if necessary to remind claimant how agreement to take part was sought.]

**Are you taking part in the trial testing the new way of collecting medical information for benefit claims using GP medical records?**

- If yes – go to section 3a
- If no – go to section 3b
- If don't know – go to section 4

### 3. Experience before taking part in the trial

#### 3a. Ask participants

**Was it clear to you what taking part in the trial would mean?**

- understanding what the trial involved
  - aware that participation was voluntary?
  - aware that GP involvement was voluntary?
  - views on GP participation
  - usefulness of DWP information (leaflet/letters/claim forms)
- perception of impact for self
  - did you think it would affect decision on claim?
- perception of impact for GP; administrative staff
- feelings about taking part – interest/curiosity; positive/negative feelings

**Overall, what made you decide to agree to take part in the trial?**

**Now go to Section 4.**

#### 3b. Ask non-participants

**Was it clear to you what taking part in the trial would mean?**

- understanding what the trial involved
  - aware that participation was voluntary?
  - aware that GP involvement was voluntary?
  - views on GP participation
  - usefulness of DWP information leaflet?
- perception of impact for self
  - did you think it would affect decision on claim?
- perception of impact for GP; administrative staff
- feelings about taking part – interest/curiosity; positive/negative feelings

**Overall, what made you decide NOT to take part in the trial?**

**Now go to Section 4.**

#### 4. Understanding of decision-making processes for recent claim/medical assessment

[Interviewer note: refer to trial arrangements for respondents who have answered Section 3. Do not mention trial for others.]

**We are interested to know whether it's clear to people how their entitlement to incapacity benefit is dealt with. Thinking about your [most] recent dealings with DWP about your incapacity benefit, can you tell me what happened [after you sent in your claim form]/[when your claim form was looked at again]?**

*Seek unprompted answers and observations first. If necessary, prompt:*

- How do you think GP has been involved?
  - what sort of information has he/she provided to DWP?
- How have local benefit office been involved?
- Anyone else (e.g. special doctors, advisors) involved? How?

**Who do you think might be involved in the next few weeks or months? How will they be involved?**

*Prompt again for GP and others' involvement*

**What sort of information do you think benefits staff need about your illness or condition and how it affects your working?**

- Kind of information
- Source of information
- How is information collected? Forms/letters, medical examinations

**How sensible does that way of collecting and using information about you seem, for deciding your entitlement to incapacity benefit?**

- Perceptions
- Beliefs and feelings
- Concerns and anxieties

**5. Check for previous claims/medical assessments to decide Incapacity Benefit entitlement**

**We have talked about your recent claim, but can I check whether you have put in a claim for Incapacity Benefit in the past?**

If yes – go to Section 6

If no – go to Section 7

If don't know – go to Section 7

**6. Previous experience of [claiming/having an assessment for] Incapacity Benefit**

*[Interviewer note: Some respondents will be re-referral claimants. We are interested in their views on how their medical test was dealt with on the most recent occasion before the trial started. Other respondents will be talking about medical tests in respect of separate past claims.]*

**Can I check about when you last had a medical assessment(s) for incapacity benefit?**

**Can you say how last time was different to this time?**

how was GP involved?

how was local benefit office involved?

how was anyone else (e.g. special doctors, advisors) involved?

**What sort of information was collected that time?**

kind of information

source of information

how was information collected? forms/letters, medical examinations

**In your view, how sensible was *that* way of collecting and using information?**

perceptions

beliefs and feelings

concerns and anxieties

**7. Deciding entitlement under the trial arrangements**

**I now want to ask (more) questions about the new arrangements for collecting medical information under trial in the Sheffield/Rotherham area.**

**May I just run through what is happening in the trial?** *Interviewer explain.*

**Do you know what information is kept in GP records?**

*Seek unprompted answers first. If necessary, prompt:*

GP's own notes

hospital letters

test results

**Do you think there are advantages in using the actual medical notes in deciding your entitlement to incapacity benefit?**

*Probe for:*

perceived advantages for self

better decisions

speed/ease of process

**Do you think there are any disadvantages?**

*Probe for:*

perceived disadvantages for self

concern about what information notes contain

not such good decisions

speed/ease of process

**We want to talk about the way in which the new arrangements affected GPs, but can I first ask about you and your GP?**

*Explore:*

length of time with GP

recent contact; nature and extent of GP involvement; same/different GPs

other medical treatment

attendance at hospital/clinic

awaiting treatment?

generally good/not good relations with GP

confidence in GP

extent to which GP knows about their work aspirations

**Do you think that if the new arrangements were introduced for all claims your relations with your GP would be affected in any way?**

*Explore:*

- improving relations
- increased pressures/tensions

#### **8. Medical examinations**

**Some people are asked to go for a medical examination as part of deciding their entitlement for incapacity benefits. Have you had a medical examination for your new, recent claim?**

**If yes, probe for experiences and views**

- Knowledge of information available to examining doctor
- Extent of doctor's knowledge about condition, and its effects on daily living and ability to work
- Did doctor refer to medical records?
- Differences from other medicals, i.e. for other benefits?
- Views on whether doctor should have report from GP, or extracts from notes made by DWP doctor.

*Probe for reasons.*

**Now ask all**

#### **Views on medical examinations**

- What kinds of people are asked to go for a medical examination
- What kinds of circumstances
- Appropriateness for finding out how illness/condition affects ability to work

*Probe for reasons*

- Appropriate role for GP notes in medical examinations

*Probe for reasons*

- Should every claimant have an examination?

#### **Respondent's preferences**

*Ask claimants who have NOT had an examination (yet)*

- Would you like to have a medical examination in connection with your claim?

*Probe for reasons*

*Ask claimants who HAVE had an examination*

- Would you have preferred NOT to have had a medical examination?

*Probe for reasons*

#### **9. Improving collection and use of medical information for deciding incapacity benefits**

**Now that we have talked about this trial in detail, do you think it is a good idea?**

- Perceived advantages
- Perceived disadvantages
- Remaining concerns/anxieties

**Knowing what you know now, would you have participated/ not participated in the trial?**

*Probe for reasons*

**How would you feel about it being introduced across the country as the new way for dealing with everybody's applications for incapacity benefits?**

*Probe for reasons*

**Have you any suggestions for better ways of deciding people's entitlement to incapacity benefit?**

**Thank you for taking part.**

## TOPICGUIDE

### Group Discussion with Jobcentre processing staff

#### Interviewer's introduction

*You were invited to take part in this research because you play a central role in the Department for Work and Pensions' pilot to test a new way of collecting information for deciding whether people are eligible for incapacity benefits. We would like to hear about your views and experience of the pilot arrangements. We are particularly interested in any comparisons you can make between the pilot arrangements and the 'usual' arrangements you are still using where GPs or claimants have opted out of the pilot.*

- Remind about SPRIU; remind about earlier visit to Sheffield Jobcentre in May
- Explain the issues to be covered
- Discussion will last around one hour
- Explain confidentiality, and how the material will be used
- Ask for permission to use tape-recorder
- Any questions or concerns?

#### 1. Identifying differences in practice under the pilot arrangements

- We want first to identify the differences in what you actually do in processing claims under the pilot arrangements compared with the 'usual' arrangements. At this stage we are not trying to assess whether these have had positive or negative effects. That will be the next task.

*Interviewer note: try to identify and distinguish (a) new activities they do, (b) things they do not do under the pilot arrangements, and (c) things they do differently.*

#### 2. Impact of pilot arrangements

- Now we want to talk about what effects these changes have had, for example how they have made your job easier (or not), and what problems (if any) have arisen.

*Interviewer note: use prompts if required.*

*Prompt: Have you had to deal with any major difficulties/bottlenecks in processing claims? How did you respond?*

*Prompt: Has there been an impact on*

- speed of processing?
- number/type of appeals

*Prompt: How have contacts with other key actors been affected?*

- other Jobcentre staff
- Medical Services doctors
- GPs
- claimants
- others?

*Prompt: Has anyone from the above groups raised any concerns about the pilot arrangements?*

*Prompt: Do processing staff have any concerns?*

#### 3. Follow up points from early site visit in May 2002

- It was very early days when we visited in May, but some points were raised that we would like to follow up.
  - IT support
  - apparent simplicity of pilot, compared with actual experience
  - effect of performance targets

#### 4. Lessons from pilot

- What are the main strengths? *Probe fully (compare with usual arrangements)*
- What are the main weaknesses/area of concern? *Probe fully (compare with usual arrangements)*
- Suggestions for improving process?

**TOPIC GUIDE****Interview with Medical Services Operation Manager****Interviewer's introduction**

*You were invited to take part in this research because you/your practice are participating in the Department for Work and Pensions trial to test a new way of collecting information for deciding whether people are eligible for incapacity benefits. We would like to hear about your views and experience of the trial.*

- Remind about SPRU
- Explain the issues to be covered
- Discussion will last around one hour
- Explain confidentiality, and how the material will be used
- Ask for permission to use tape-recorder
- Any questions or concerns?

**1. Impact of pilot arrangements**

- What have been the main differences in processing pilot and non-pilot cases?  
*probe: speed*
- What determines the flow of work to the doctors?
  - are certain types of case reserved for particular doctors?
  - impact? e.g. speed of processing
- How has Tracker system of case control worked? Have any useful lessons emerged?
- Do you organise the collection of additional information when requested by approved doctors?  
*probe: who, how often, response rate, timing*

**2. Lessons learned from the pilot**

- What have been the main strengths and weaknesses of the pilot arrangements?
- How could processing of cases be quicker?

**TOPIC GUIDE****Interviews with approved doctors****Interviewer's introduction**

*You were invited to take part in this research because you play a role in the Department for Work and Pensions trial to test a new way of collecting information for deciding whether people are eligible for incapacity benefits. We would like to hear about your views and experience of the trial.*

- Remind about SPRU
- Explain the issues to be covered
- Discussion will last around one hour.
- Explain confidentiality, and how the material will be used.
- Ask for permission to use tape-recorder.
- Any questions or concerns?

**Interviewer note:**

Medical practitioners play a variety of roles in the administration of incapacity benefit. These are referred to in this report as *approved doctors*. The key role of the *approved doctor* in the Medical Evidence Gathering Pilot included

- preparing a data extract from GP case files (on form SB2),
- advising decision makers on paper evidence for exemption/scrutiny cases,
- advising decision makers following an examination of the claimant (when they act as an Examining Medical Officer (EMO)).

Ask questions in Sections 2 and 3 accordingly.

**1. Background/medical experience**

- Current role
- Number of sessions
- Other (concurrent/previous) employment
  - Experience of General Practice (no. of years; years since working as GP)
  - Specialisms/areas of expertise

## 2. Extracting information from GP notes

- Is the process of extraction the same for (a) exemption stage and (b) scrutiny stage?

*Probe for differences*

- How do you identify 'relevant information' as defined in the context of a claim for incapacity benefit for (a) pilot and (b) non-pilot cases? *Probe for differences.*
  - how do you decide what to include/exclude on the SB2 form?
- How easy/difficult is it to extract relevant information?
  - what makes a case 'easy' or 'difficult'?
- How variable are GP notes?
  - do they contain relevant information of value to the issues for which an approved doctor has to provide advice?
  - what information, if any, is missing?
- Do you ever need further information other than what is in GP notes?
  - What do you do in such circumstances?
- Any comments on design of form SB2?

*Probe*

- Is there a difference between handwritten and computerised GP notes?

*Probe for differences and impact/legibility*

- How long does extracting information take? *Probe for range of times*

- is this a problem? *Probe*

## 3. Experience of exemption and scrutiny

### (a) Exemptions

- Experience of EXEMPTION cases in the pilot (no. of cases; frequency)
- Experience of NON pilot cases (no. of cases; frequency)
- Comparison between pilot and 'usual' arrangements
  - what information is available under 'usual' arrangements?
  - do you need to contact GP for any reason? *Probe*
  - in pilot, how much of GP notes do you need to refer to? (e.g. no. of years)
  - is it easier to decide exemptions under pilot? *Probe for reasons*
  - have you made *more* exemption decisions in the pilot?
  - do you find that the evidence from the GP notes has helped to increase your level of confidence in the advice given (to exempt or not)? *Probe*
  - time needed for exemption cases
  - has task changed for some types of case more than others? (e.g. type of disability)? *Probe for examples*
- How would you summarise the relative pros and cons of using GP notes compared with 'usual' arrangements? *Probe fully*

### (b) Scrutiny

- Experience of SCRUTINY cases in the pilot (no. of cases; frequency)
- Experience of scrutiny of NON pilot cases (no. of cases; frequency)
- Comparison between pilot and 'usual' arrangements
  - what information is available under 'usual' arrangements?
  - do you need to contact GP for any reason? *Probe*
  - how much of GP notes do you usually need to refer to? (e.g. no. of years)
  - are there cases where five years is *not* enough? *Probe*
  - is it easier to give clear/unambiguous advice (i.e. to pass or not pass the case) under pilot? *Probe for reasons*
  - Compared with non-pilot cases where an IB 113 or Med 4 is available, has number of cases where there is insufficient information to decide fallen?
  - Using the information from the GP notes, are you more confident about the advice you give (to accept or call for exam)? *Probe*
  - how long does process take? any preference compared with standard scrutiny work?
  - has scrutiny task changed for some types of case more than others? (e.g. type of disability)? *Probe for examples*
- How would you summarise the relative pros and cons of using GP notes compared with using (a) IB113s and (b) Med4s? *Probe fully*
- 'Rework' claims - has pilot affected number, type, content of 'rework claims? *Probe fully.*
- Views about practice staff being used to draft IB113s.

## 4. Medical examinations

- What has been the effect on the task of examining claimants of replacing the IB113 or Med 4 with the SB2?
- In what way is information in SB2 different to information in non-pilot cases? *Probe fully for advantages and disadvantages of differences.*
- How is information on SB2/IB113/Med4 used? *Probe for differences*
  - before the examination (in preparing to see claimant)
  - during the examination (e.g. discussing contents with claimant)
  - afterwards in completing the IB85?
- Views on having copied extracts from GP notes in SB2 *Probe for pros/cons. Compare with information from scrutiny doctors.*
- Explore perceptions of:
  - differences in content/depth of information on IB85
  - confidence in their advice recorded on IB85, e.g. on functional ability and re-referral period



- Explore perceptions of differences in type of case being referred for examination. *Prompt:*
  - more/fewer cases seen at examination that are clear exemptions?
  - more/fewer cases seen at examination that are 'obvious' allowances or disallowances?
- Preference for new or 'usual' arrangements?
- How could the pilot arrangements be changed to be more useful?
- How could the 'usual' arrangements be changed to be more useful?

#### 5. Improving collection and use of medical information for deciding incapacity benefits

- What is the most suitable time period for GP notes (to balance need for all relevant information, administrative efficiency, and client confidentiality)? *Probe*
  - any difference for referral and re-referral cases?
- Are GP case notes or current arrangements more likely to enable Medical Service doctors to gain a clear and accurate picture of a claimant's level of incapacity?
- How would you feel about arrangements to use GP case notes being introduced across the country as the new way of collecting clinical information on incapacity benefit claimants?

*Probe for reasons*

- Are new arrangements appropriate for all incapacity benefit claimants or some only?

*Probe*

- How best do you think factual clinical information about the claimant/ patient's condition could be obtained to inform benefit assessments?

#### TOPIC GUIDE

##### Interviews with Jobcentre Plus decision makers

#### Interviewer's introduction

*You were invited to take part in this research because you play a central role in the Department for Work and Pensions' pilot to test a new way of collecting information for deciding whether people are eligible for incapacity benefits. We would like to hear about your views and experience of the pilot arrangements. We are particularly interested in any comparisons you can make between the pilot arrangements and the 'usual' arrangements you are still using where GPs or claimants have opted out of the pilot.*

- Remind about SPRIU
- Explain the issues to be covered
- Discussion will last around one hour
- Explain confidentiality, and how the material will be used
- Ask for permission to use tape-recorder
- Any questions or concerns?

#### 1. Role of decision maker

- What is your role in deciding:
  - exemption cases,
  - cases passed on scrutiny,
  - medical examination cases?
  - Who else is involved?
- Roughly how many cases have you dealt with under the pilot arrangements?
- In general, how easy is it to make decisions on Personal Capability Assessments? What are the main issues and areas of concern/difficulty?
- How frequently do you find yourself coming to a different conclusion to an approved doctor on a case?
  - under what circumstances is that most likely to happen?

## 2. Impact of pilot arrangements

*[Interviewer note: Explore differences between pilot and 'usual' arrangements on the following aspects of decision makers' work. Probe responses fully.]*

- speed and efficiency of processing
  - time needed
  - number of cases returned to Medical Services for 'rework'
- process of decision making
  - need to contact others (e.g. other Jobcentre staff; approved doctors; GPs; claimants; others)
  - need to consult guidance/reference material
  - are pilot arrangements particularly suitable or unsuitable for certain kinds of case? *Probe for type of case where GP notes/SB2 particularly useful*
- quality of medical evidence
  - changes in content/depth/clarity of medical advice from approved doctor
  - has quality of the examining doctor's advice improved on the IB85?
  - do you agree or disagree more with the approved doctor's advice on the IB85 report? Why?
- quality of own decisions
  - are your decisions 'better' in any way? *Probe*
  - do you have more confidence in own decisions? *Probe for reasons*
  - is new approach to evidence gathering likely to have any impact at the appeal or re-consideration stage?
  - is supporting advice/guidance material sufficient? *Probe for gaps/weaknesses*
- Has the impact of the pilot been different for new and re-referral claims? *Probe fully.*

## 3. Overall view of pilot arrangements

- What are main strengths? *Probe fully (compare with usual arrangements).*
- What are main weaknesses/area of concern? *Probe fully (compare with usual arrangements).*
- Suggestions for improving process



# Appendix C

## Letters



**DWP** Department for  
Work and Pensions

Our address	Social Research Branch Department for Work and Pensions 4 <sup>th</sup> Floor The Adelphi 1-11 John Adam Street London WC2N 6HT
Our phone number	0207 962 8003
Our fax number	0207 962 8542
Email	jo.bacon@dwp.gsi.gov.uk
Website	<a href="http://www.dwp.gov.uk/asd/">www.dwp.gov.uk/asd/</a>
Date	4 October 2002
Reference	

Dear

### **Evaluation of Medical Evidence Gathering for Incapacity Benefit pilot**

I am writing to ask for your help with this important research study.

As you may know, the Department for Work and Pensions (DWP) is piloting a scheme with GPs and benefit clients in the Sheffield and Rotherham areas that involves collecting medical evidence for Incapacity Benefit claims directly from patients' case notes.

In order to evaluate the pilot, the Department has appointed the Social Policy Research Unit (SPRU) at York University to undertake qualitative research with the various groups of people who were invited to take part in the scheme, including those General Practices which decided not to take part. These face-to-face qualitative depth interviews will allow the researchers to fully explore the views of non-participating practices, which will be important in helping us to gain a fully rounded assessment of the pilot.

The value of the research depends on the willingness of practices and individuals to take part. So, I very much hope that you or one of your colleagues will be able to spare the time to speak to a researcher from SPRU. Everything that is said to the researchers will be treated in strict confidence. Their report will not identify individuals or practices and details of these will not be passed to anyone outside of the research team.

You will find enclosed a letter from SPRU setting out how they would like your practice to participate in the research and a summary sheet explaining the full range of work they are carrying out for DWP.

If you would like to know more about this research, please call me, Jo Bacon, on 020 7962 8003 or either of the two principal researchers at SPRU, Dr Roy Sainsbury and Anne Corden, on 01904 433608. We will be happy to answer any queries you may have.

Yours sincerely

Jo Bacon  
Senior Research Officer  
Department for Work and Pensions



RS/RD

Title

Address

Email: rds2@york.ac.uk

Date

Dear

**Evaluation of Medical Evidence Gathering for Incapacity Benefit pilot**

As explained in the letter from Jo Bacon, the Department for Work and Pensions has commissioned the Social Policy Research Unit at the University of York to conduct research on the pilot project on Medical Evidence Gathering for Incapacity Benefit.

It is important that we seek the views of this way of supplying evidence among General Practitioners not only from those who have been participating in the pilot but also from those who have decided not to participate. One of the research team will be telephoning you shortly, and we hope that you will agree to meet and take part in a research interview, at a time and place convenient to you.

Topics for discussion in the interview include:

- your reasons for declining to take part in the evidence gathering pilot
- your experiences of existing processes
- your views about using patients' case notes in this way
- your suggestions for improving medical evidence gathering arrangements more widely.

The discussion will take about 45 minutes to one hour, and we are able to offer an honorarium of £75. Everything discussed will, of course, be dealt with in confidence.

We thought it would be helpful to enclose here a summary of the overall research design.

We hope that you will be interested in taking part in this research and will be able to offer us an appointment.

Yours sincerely

Dr Roy Sainsbury



### **Information about research on the Medical Evidence Gathering pilot**

#### *The Medical Evidence Gathering pilot*

The aim of the pilot is to test alternative arrangements designed to provide Jobcentre Plus Decision Makers and Medical Services doctors with better evidence on which to base decisions about eligibility for Incapacity Benefit and to reduce benefit related paperwork for GPs.

The pilot has been running in the Sheffield/Rotherham area since January 2002. People applying for Incapacity Benefit who agree to take part, and whose GPs have also agreed to take part, are assessed for eligibility on the basis of evidence taken directly from medical case notes.

#### *What is the Social Policy Research Unit?*

The Social Policy Research Unit is an independent research unit within the University of York. It is known for high quality research to inform social policy in areas including health and social care, family policy, employment, and disability. Funding comes from a variety of sources, including major government departments.

The research team for this qualitative enquiry into the Medical Evidence Gathering pilot are Dr Roy Sainsbury, Anne Corden, Professor Peter Kemp, and Hanif Ismail, who between them have considerably experience in evaluative research on the administration and delivery of services and benefits.

### **Qualitative Research on the Medical Evidence Gathering pilot**

The aim of SPRU's research is to evaluate the pilot in relation to:

- the impact on GPs
- quality of medical evidence given to Benefits Agency Decision Makers
- the impact on decision-making
- the overall effectiveness of the new procedures.

SPRU will seek views and experiences of the pilot among the key groups of people:

- GPs taking part in the pilot
- GPs choosing not to take part in the pilot
- GP practice staff involved at a procedural level
- applicants for Incapacity Benefit who are taking part in the pilot
- applicants for Incapacity Benefit choosing not to take part
- Benefits Agency processing staff and Decision Makers
- Medical Services doctors.

Information will be sought in personal interviews and group discussions, and dealt with in confidence. A draft report of the findings will be passed to the Department for Work and Pensions in early 2003, and a final report agreed by March 2003. Results will be published, and made available in summary form to people who contributed to the research.

Further information about the pilot is available from Jo Bacon at the Department for Work and Pensions on 020 7962 8003.

**DWP** Department for  
Work and Pensions

Name and Address

Our address

Social Research Branch  
Analytical Services Directorate  
4<sup>th</sup> Floor Adelphi  
1-11 John Adam Street  
London WC2N 6HT

Our phone number

0207 962 8003

Our fax number

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Email

jo.bacon@dwp.gsi.gov.uk

Website

www.dwp.gov.uk/asd/

Date

19 June 2002

Reference

Dear

**Benefits and medical records**

I am writing to ask for your help with some important research that is being carried out among people who have recently made a new claim for incapacity benefit or whose claim is being reassessed. The Department for Work and Pensions is testing a new way of collecting medical information for benefit claims by using GP medical records, and we would like to find out what people think about it. The research is being carried out on behalf of the Department by an independent research organisation, the Social Policy Research Unit at the University of York.

A researcher from the Social Policy Research Unit may contact you soon to see whether you are willing to be interviewed as part of the study, and if so to arrange a time to meet with you. The interview would last about an hour. Anything you say to the researcher will be strictly confidential; your name and personal details will not be passed to any government department or anyone else. *Everyone who is interviewed will be given £15 as a small token of thanks for their help. Taking part in this study will not affect any benefit you receive, or any dealings you may have with any government department or agency.*

When the researcher gets in touch they will tell you more about the research and answer any questions you might have. Please let us know if there is anything we can do to make it easier for you to take part. The researcher who contacts you will also be glad to talk about any requirements you may have or arrangements that would be helpful.

I do hope you decide to take part in the study – the value of the research depends on people's willingness to help. If, however, you do not wish to take part, please let us know by Thursday 4 July quoting the reference number at the top of this letter. You can either write to us at the FREEPOST address above, or telephone the research team secretary, Sally Pulleyn on 01904 432626. If you would like to know more about the research, you can also call me, Jo Bacon, on 0207 962 8003.

Thank you for your help. I hope you will be able to take part in this important study and enjoy talking to the researcher.

Yours sincerely

Jo Bacon  
Senior Research Officer



# Appendix D

## Administrative context of Incapacity Benefit decision making

### D.1 Incapacity benefits

State incapacity benefits provide a replacement income to people below state pension age who have to stop working or looking for work as a result of sickness or disability.

People gain entitlement to one of the incapacity benefits depending on whether they have:

- (a) paid enough National Insurance contributions on their earnings, and
- (b) satisfied the relevant medical test.

#### D.1.1 National Insurance Contributions

If a person has paid or been credited with a minimum level of National Insurance contributions (NICs) and they satisfy the relevant medical test (see below) they will be entitled to contributory *Incapacity Benefit (IB)*.

If a person has not paid enough NICs but satisfies the relevant medical test, he or she can get National Insurance Credits. If they have a low income, then they can claim *Income Support (IS)* on the grounds of incapacity. People may also be able to get IS to top-up their IB where they have no other income.

If a person has not paid enough NICs, but has been treated as incapable of work for at least 196 days and that period of time began before the age of 20 (25 for those in education or training before age 20) he or she is now able to claim IB. Before April 2001 they would have claimed *Severe Disablement Allowance (SDA)* as would others who satisfy the 196 day test and were classified as 80 per cent disabled. SDA was abolished from April 2001 for new cases but existing recipients continue to receive it.

### D.1.2 Relevant medical test

There are two different tests of incapacity that apply in different circumstances the *Own Occupation Test* and the *Personal Capability Assessment*.

People who have been working recently need to satisfy the *Own Occupation Test*. This is a test that looks at whether ill-health or disability stops a person from doing their *normal* job (with adjustments where necessary). A certificate from a medical practitioner, usually the person's GP, is normally sufficient to satisfy this test.

Employees need to satisfy an own occupation test to get Statutory Sick Pay (SSP). SSP is paid for up to 28 weeks. However some people who have been in employment are able to claim IB straightaway because they cannot get SSP. This group is made up of the self-employed, employed earners getting less than £75 per week, and people who have only recently become unemployed or whose contracts ended while they were sick. This group needs to satisfy the own occupation test for their first 28 weeks on benefit.

After 28 weeks on an incapacity benefit the groups affected by the Own Occupation Test are required to satisfy a different test, the *Personal Capability Assessment (PCA)*. All other clients are required to satisfy the PCA from the outset of their claim. This includes those who have been unemployed or otherwise out of work and those moving across after 28 weeks on SSP.

The PCA (previously known as the 'All Work Test') is the medical test that is used to decide entitlement to longer-term state incapacity benefits. In contrast to the Own Occupation Test, it looks beyond ability to perform the normal occupation to look at the extent to which a person's condition affects their ability to do a range of everyday work-related activities covering:

- physical functions such as walking, bending and kneeling, sitting in a chair;
- sensory functions such as ability to speak, hear or see; and
- mental functions such as interacting with others and coping with pressure.

Approved doctors working for Medical Services on behalf of DWP assess the extent to which a person's health condition impairs their ability to perform any of these key activities. They then provide advice to a benefit *decision maker*. A person satisfies the PCA if their ability to perform any *individual* activity is seriously curtailed (for example they cannot walk more than 50 metres without stopping, or they cannot turn the pages of a book). Alternatively the PCA can be satisfied if there is a lesser degree of impairment *across a number of activities* (for example a person cannot stand up without holding onto something and cannot see well enough to recognise someone at 15 metres). It can also take account of the combined effect of mental and physical health problems.

Importantly, the PCA is not a test that distinguishes between people who can and cannot work. Rather it draws a line between people who should not be expected to seek work in return for benefit (those satisfying the PCA who stay on IB) and those who can be expected to do so (who can attempt to move back to work or claim JSA).

Around 20-25 per cent of people on IB have very severe medical problems and are exempt from the PCA process. This group includes, for example, those who are already in receipt of highest rate care component of Disability Living Allowance, those with terminal illnesses and those with severe conditions like tetraplegia, chronic degenerative disease and schizophrenia.

The PCA process requires the collection of evidence to inform the advice which the approved doctor provides to the decision maker and will involve some or all of:

- a request for information from the doctor issuing sickness certificates;
- in most cases, the completion of a detailed questionnaire by the customer about the impact of their condition on the work-related activities;
- consideration of the paper evidence by an approved doctor to advise whether the customer's self-assessment is supported by the medical evidence (paper scrutiny);
- in about a third of cases, where further evidence is required, a face-to-face medical examination with an approved doctor.

Approved doctors provide medical advice in relation to the PCA to a Jobcentre Plus decision maker who makes the decision on benefit entitlement. Because of the need to collect sufficient evidence, the entire PCA process can take some time to complete. In the meantime, incapacity benefits can be put into payment supported by evidence from the patient's own doctor.

Where a person does satisfy the test, a date will be set on medical advice for a further PCA to identify whether a person's condition has improved. Usually this is at an interval of between 3 and 18 months, depending when a change might be expected. Even where significant change is unlikely, cases are checked periodically. Procedures were standardised in May 2001 so that all cases going through the PCA are scheduled for consideration of a further test at least after 3 or 5 years (except for a small number of people with severe conditions where this would clearly be inappropriate).



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